UNDERSTANDING THE CURRENT DIAGNOSIS AND MANAGEMENT OF ATTENTION DEFICIT HYPERACTIVITY DISORDER (ADHD): A QUALITATIVE APPROACH

By

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DECLARATION

This work, or any part thereof, has not previously been presented in any form to the University or any other body whether for the purpose of assessment, publication or any other purpose (unless otherwise indicated). Save for any express acknowledgements, references, and/ or bibliographies cited in the work, I conform that the intellectual content of the work is the result of my own efforts and of no other person.

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ABSTRACT

Aims: The aim of this research was to engage with the experiences of professionals, parents, and young people in order to develop an understanding of the current diagnosis and management of ADHD. This research will be of interest to Counselling Psychologists working with the child and adolescent population and the clinical area of ADHD.

Method: Nine semi- structured interviews were conducted with two young people, three parents, and four professionals. The interviews were transcribed and analysed using the principles' of grounded theory methods. A constructivist version of grounded theory was implemented, as outlined by Charmaz (2006) and a social constructionist epistemology was adopted.

Analysis: A central story line of 'investing in ADHD' emerged. This involved the investment of resources in the 'simple truth' of ADHD as existing within the child's brain. A number of categories emerged which contributed to this position, including the 'battlegrounds' which were fraught with struggles to gain control of children's difficult to manage behaviours and 'knowledge and understanding' which highlighted the need to understand the nature of the perceived problems. In addition, 'social expectations' and 'personal conflicts' depicted the social and personal factors which served to construct the perceived problems.

Conclusion: The investment in the 'simple truth' of ADHD appeared to hold the most meaning for those involved in the study. These findings offer utility for Counselling Psychologists wishing to engage clients in psychological formulation and management approaches which aim to address the underlying factors which influence ADHD.

1 Introduction

Attention Deficit Hyperactivity Disorder (ADHD) as a diagnostic concept has received extensive attention in research, media, education, and clinical settings. Nonetheless, debates and controversies continue to exist over its diagnosis and management. ADHD is primarily characterised by the three core features of impulsivity, inattention, and motor excess.

The current National Institute for Health and Clinical Excellence (NICE) guidelines document the aetiology of ADHD as interplay between genetic and environmental factors and state that a diagnosis should not imply a medical or neurological cause (NICE, 2009). Yet current practice appears to be based upon the notion of ADHD as a neurological disorder. In addition, much of the existing research provides a focus on aetiology, diagnostic criteria, and treatment efficacy. However, within current research there appears to have been a shift in understanding of ADHD away from brain dysfunction towards a concept of a heterogeneous set of related behaviours (Taylor, 2009). In reviewing past and present research into the causes of ADHD, categories of organic, environmental, genetic, and cognitive factors are identified. Whilst it now appears to be accepted that neurological structures do differ within individuals diagnosed with ADHD and those displaying 'acceptable' behaviour, no identified cause has been established. Despite this shift in understanding, minimal research exists which examines alternative explanations of ADHD and how inattention, hyperactivity, and motor excess within the individual, interact with and relate to the environment.

Challenges to the current practice of ADHD suggest it is more suitably regarded as a 'cultural construct' and cite criticisms over the use of medication to treat children and young people (Baldwin & Cooper, 2000; Timimi & Taylor, 2004). Furthermore, concerns have arisen over the growing prevalence of ADHD diagnosis in the western world (Timimi et al., 2004). Consequently, the economic implications of managing such a prevalent problem, through both financial costs and detriment to quality of life have been highlighted (Hakkaart-van Roijen et al., 2007). Despite these documented concerns and the publishing of the NICE guidelines, research into the biological origins of ADHD continues to outweigh studies which focus on alternative explanations. It is suggested here that by continuing to adopt a medical model approach valuable insights into ADHD are being overlooked and treatment options are being limited. In order to inform current practice a more robust base of research is required which explores the impact of current practice and alternative explanations of externalised behaviour patterns in children. The current research therefore, aims to bridge this gap in research, by adopting a qualitative approach to understanding the diagnosis and management of ADHD.

Following a review of existing literature, the aims and rationale of the current research are outlined. The research is then reported, including the methods adopted, a write up of the analysis, and a discussion of the research findings. In addition, consideration is given of the contribution to clinical practice and Counselling Psychology, the limitations of the research, and the implications for future research. Finally, a critical appraisal of the research process is provided.

2 Literature Review

In reviewing the related literature, a dichotomy emerges between views of ADHD as a medical or a cultural construct. This review appraises ADHD research over the past decade and suggests that in order to move forward a more balanced body of research is required. Such research should aim to acknowledge the difficulties associated with children's externalised behavioural difficulties whilst attempting to further our understanding of how these behaviours relate to a child's social, cultural, and environmental context. In doing so, it is argued that research originating in the psychological field and adopting a qualitative framework may serve to bridge the gap between divergent understandings of ADHD.

2.1 Literature search method

Relevant published literature was identified through searches of the following electronic databases: Psychoinfo, ScienceDirect, Ingenta Connect, Cinahl and Swetswise for the years 2000 to 2011. This was accompanied by the use of internet search engines with particular focus on sites specific to ADHD and The Department of Health. Keywords in all the searches were ADHD, Attention Deficit/ Hyperactivity Disorder, Attention Deficit Hyperactivity Disorder, parents, children, adolescents, experiences, management, treatment, diagnosis and medication. Relevant literature from the reference lists of identified articles were followed up. Literature was obtained through The University of Wolverhampton's Online Public Access Catalogue (OPAC) and orders from the British Library holdings. Articles were included if they were relevant to the review in question and were fully referenced to their original source.

2.2 What is ADHD?

The concept of ADHD as a medical diagnosis has become widely accepted. The current American diagnostic criteria detailed in the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV) describes broad based criteria characterised by early onset, significant inattention, impulsivity, and over activity, all of which are developmentally inappropriate and should be associated with functional impairment (American Psychiatric Association, 2000). The narrower International Classification of Diseases and Health Related Problems (ICD-10) define ADHD as a hyperkinetic disorder stating that it is:

> "a group of disorders characterized by an early onset (usually in the first five years of life), lack of persistence in activities that require cognitive involvement, and a tendency to move from one activity to another without completing any one, together with disorganized, ill-regulated, and excessive activity. Several other abnormalities may be associated. Hyperkinetic children are often reckless and impulsive, prone to accidents, and find themselves in disciplinary trouble because of unthinking breaches of rules rather than deliberate defiance. Their relationships with adults are often socially disinhibited, with a lack of normal caution and reserve. They are unpopular with other children and may become isolated. Impairment of cognitive functions is common, and specific delays in motor and language development are disproportionately frequent. Secondary complications include dissocial behaviour and low self-esteem" (World Health Organisation, 2007, Chapter V, p. 100).

Such definitions have attracted debate around the concept of ADHD, due to their description at a behavioural level and a lack of cognitive, metabolic, or neurological

markers specific to neurological disorders (Baldwin & Cooper, 2000; Timimi et al., 2004).

The existence of a debate within ADHD practice can be identified through the publishing of the 'International Consensus Statement on ADHD' (Barkley, et al., 2002) and the opposing 'Critique of The International Consensus Statement on ADHD' (Timmi, et al., 2004). Within the consensus statement, a consortium of scientists sought to claim the status of ADHD as valid and condemned those who challenge current ADHD research and practice. The publishing of the critique of the international consensus agreement illustrates the contrasting opinions of those who wish to highlight the cultural perspective of ADHD. Those opposing the consensus statement suggest that such a document acts to prevent further discussion around a diagnosis prior to establishing an exact cause. As Double (2002) succinctly highlights, to make the case for more understanding of ADHD in the context of social explanations is not refuting its existence, but questioning current practice. In addition, as Double (2006) argues a biomedical approach reduces people to objects that need their biology cured, which in turn encourages an avoidance of understanding the context of presentations, such as ADHD. Therefore, a questioning approach to ADHD is not denying the importance of biological explanations but striving to understand the impact of existing approaches. In addition, it identifies the importance of understanding how behaviours have developed within a social context.

2.3 Controversies with diagnosis

Inconsistencies in the current body of literature concerning ADHD relate to debates around the basis of psychiatric diagnosis. Writers who adopt this critical position argue

that the empirical basis upon which diagnosis stands is flawed (Bentall, 2007; Boyle, 2007; Pilgrim, 2000; Szasz, 1970). Psychiatric diagnosis assumes a scientific narrative, therefore, implying that it follows the principles of medical systems. This suggests that researchers can provide an explanation of the relationship of phenomena by identifying an underlying biological or psychological process. However, studies continue to 'discover' the biological basis of ADHD and whilst a variety of hypothesis have emerged they remain inconclusive as to an exact cause (Durston, 2003; Kieling, Concalves, Tannock & Castellanos, 2008). There has been a range of criticisms of the merits of the ADHD diagnosis, which originate in the assumptions of, and empirical basis for, psychiatric diagnosis.

The DSM documents several combinations of behaviours used to classify ADHD throughout the various editions. It has been suggested that these changes within the classification of ADHD imply that the foundation of the diagnosis remains unstable and inconsistencies in its application continue to exist (Egger & Emde, 2011; Gaub & Carlson, 1997). In addition, problems with a scientific classification system have been related to the diversity of 'symptoms' within diagnostic categories. Wide ranging and subjective classification can result in overlap of 'symptoms.' This often creates the need for 'dual diagnosis' or 'co-morbidity' that can further pathologise individuals who meet several diagnostic criteria (Boyle, 2007). High co-morbidity rates for ADHD have been noted. Such studies suggest that approximately 60–70% of children with ADHD have comorbid or co-existing conditions. These include conduct disorder, learning difficulties, depression, anxiety, and obsessive-compulsive disorder (Barkley, 1998; Wheeler, Pumfrey & Wakefield, 2009; Wilens, Bierderman, Brown, et al., 2002). These comorbidity rates influence the presentation, diagnosis of, and treatment for ADHD.

Subsequently, this has implications for practice and influences the burden of ADHD and morbidity rates. Further research has argued for the classification of ADHD subtypes to address this (Jensen, Arnold, Swanson, et al., 2007; Jensen, Martin & Cantwell, 1997). However, criticisms of psychiatric diagnosis suggest that revisions in diagnostic criteria and identification of subtypes reflect their lack of reliability (Kutchins & Kirk, 1999; Szasz, 1970). In addition, it has been argued, that loose, subjective criteria, and a lack of an agreed medical basis or diagnostic tool has led to ADHD becoming used as a blanket term. This serves to label children rather than understand the nature of their problems (Radcliffe & Timimi, 2004).

Problems with validity of psychiatric diagnosis occur when we distinguish between normal and abnormal states. For example, research has highlighted that the 'normal' phenomenon of 'inner speech' can also account for the 'psychotic' complaint of auditory-verbal hallucinations (Bentall, 2007). When applied to the diagnostic criteria for ADHD many behaviours can be seen as the child's way of adapting to their environment and therefore, context dependent (Brown, 2004). For example, within an environment of trauma or abuse much of the behaviours used to diagnose a child with 'ADHD' may be present (Myatt, 2004). Indeed many of the behaviours outlined in diagnostic criteria for ADHD, such as, 'impulsiveness and recklessness' could be applied to any child growing up. However, decisions remain subjective regarding the level of 'functional impairment' or whether behaviour is considered 'developmentally appropriate' (Radcliffe & Timimi, 2004).

Taylor (2009) reviews the development of ADHD over the last 50 years and suggests that ADHD enjoys more robust findings than is usual for complex psychiatric disorders

yet calls for further research into subtypes. In addition, three papers published in the Journal of Child Psychology and Psychiatry provide interesting insights into ADHD and emotional regulation (Martel, 2009), cognitive approaches to ADHD (Chan et al., 2009) and the process of gene-environment interaction (Sonuga-Barke et al., 2009). Snowling (2009) describes this as a welcomed move towards multi-disciplinary perspectives in ADHD and goes as far as to describe ADHD as a dimensional trait rather than a categorical disorder. This shift in the focus of research further highlights the need to continue to make links between the individual and their environment, including an understanding of how societal and cultural factors influence the individual, families, and wider social structures.

2.4 The social construction of ADHD

Those who adopt a critical perspective of ADHD have argued that a reliance on the diagnostic process serves to locate a problem within the individual and moves away from an appreciation of the individual within the historical and social context. This in turn controls the way we as a society thinks about our problems (Kutchins & Kirk, 1999). Such arguments propose that by labelling children with ADHD psychoactive medications have been used in an attempt to control behaviour and parents are becoming dependent upon 'experts' to help their child 'fit in' (Newness & Radcliffe, 2005). This draws into focus the notion of diagnostic systems as constructs of socially created values and norms, which engage the need to label and make sense of difference. Such perspectives may acknowledge diagnostic manuals as merely indicative of 'conditions of interest', which do not always claim scientific empiricism. Consequently, what then becomes labelled a 'disorder' is socially constructed (Bolton, 2004).

Concerns over the growing use of psychoactive medications and the potential impact of diagnostic practice suggest that a social constructionist framework may offer an alternative way of understanding ADHD by appreciating the social context in which the behaviour occurs.

Social constructionist theory offers a critical alternative in psychology, which utilises postmodernist and critical discourses, and allows the deconstruction of existing and taken for granted knowledge (Burr, 1995). It thus focuses on language and discourse as a way of creating meaning in society (Parker, 1992). Levine (1997) identified the need for constructionist notions to begin to influence the concept of ADHD and called for a 'person-in-environment' approach to assessment and intervention, thus constructing the problem as embedded within shared interactions between individual and environment. Levine suggests that it is essential to identify environmental barriers to a fulfilled sense of self, and to develop an understanding of the social discourses, which have contributed to the notion of ADHD as a medical condition.

Mass media contributes to the construction of meaning within society. Research into media reports of ADHD identified how these discourses define 'normal' childhood behaviour in opposition to the 'abnormal' behaviour of children with ADHD (Norris & Lloyd, 2000). Such discourses create representations of ADHD that shape and form the social world. Norris & Lloyd (2000) identified a strong parent's voice emerging from newspaper articles, which portrayed a group of mothers at 'their wits end' and 'in need of expert help'. They document how media has advocated the diagnosis of ADHD, and parents have been reported as relieved that there was a medical cause for their child's problem. In addition, parents reported feeling that something could be done which possibly would serve to mitigate them from the stigmas associated with their child's

behaviour. Such stigmas have included the notion of ‘poor parenting’. Norris and Lloyd (2000) interestingly highlight that professional opinion on ADHD in the media came predominantly from those who run private clinics, diagnose and prescribe for ADHD, and that quotes usually focused on the biological causes of ADHD. Within a social constructionist framework, these factors can be seen to contribute to an overemphasis on medical explanations of ADHD. Some evidence of a debate concerning ADHD was evident in the media; however, medical discourse far outweighed alternative ways of understanding ADHD. Norris and Lloyd concluded that despite the thousands of academic articles documenting the ADHD debate, media discourses shape both parents’, and professionals’ understanding and treatment of young people. Eleven years after this article was published, the topic of ADHD continues to feature frequently in the media.

Danforth and Navarro (2001) studied how everyday lay discourse in non-professional settings constructs meaning in ADHD. They identified two competing ideas of ‘behavioural conformity’ and ‘academic achievement’ in school discourses. In addition, school was seen as an ‘identity construction’ site that seeks to control those who do not conform or fail to thrive in school environment. Other themes that emerged included the use of medical language in lay discourse, and biological versus moral responsibility for ADHD. Within this study, medication was seen as insufficient to manage the perceived problems. Consequently, medication use whilst cited as a requirement for the child with ‘ADHD,’ was also believed to increase problems, such as, unwanted side effects and effects on self-identity (Danforth & Navarro, 2001). This suggests that within this study discourses, which serve to construct ADHD as a biological disorder, may also contribute to the maintenance of the socially constructed difficulties, which originated

in the school environment. In reviewing the studies that seek to examine and interpret the role of discourses in relation to ADHD, insights have emerged regarding construction of meaning and ways people have internalised, challenged and resisted dominant discourses. However, such research in relation to ADHD remains limited.

2.5 Social and Psychological models of ADHD

Social models of understanding, suggest that a number of factors present in modern western society can directly influence the emotional wellbeing of children and families today and contribute to behaviours associated with 'ADHD'. Furedi (2006) highlights a current problem in the breakdown of moral authority of adults, particularly what he describes as a reduction in responsibility for guiding and socialising children. He suggests that a breakdown in adult solidarity has left them reluctant to intervene when a child misbehaves. Furedi concludes that this leaves young people's behaviour uncontained by those responsible in our society. In addition, Furedi (2008) suggests that childrearing and parenting is often criticised within political arenas. He suggests that this undermines parents' confidence and intensifies a sense of insecurity and anxiety regarding children's lives, resulting in parents feeling blamed for social difficulties. The concept of power is crucial here; in researchers' avoidance of the social dimension, concepts of responsibility have moved from seeing 'mental illness' as objective and the result of mechanisms beyond our individual responsibility, towards locating the problem within the individual. It is this notion, as 'self-as-centre' that directly impacts on our conscience, and which allows those in power to exert social control and divert attention from distal causes of distress (Smail, 2005). Furthermore, the growth of psychiatric practice and use of its language in lay discourse has led to misuses of its technical words, which have diffused into everyday language, suggesting that diagnosis

may be inappropriately applied within society (Rentoul, 1995). Rowe (2005) believes that prevailing medical discourses have therefore served to label arguably normal behaviour.

It therefore appears that explanations of behaviour have moved away from causes within society, placing them within the child. This has created the need to control children's behaviour rather than address social causes of distress. This is consistent with feminist ideas of a 'mother-blame' society where mothers parenting abilities are seen to be judged according to their child's outcomes (Blum, 2007). The era of 'brain-blame' is seen to reduce the blame placed on mothers. However, Blum suggests that this notion requires mothers to work harder to overcome difficulties in a competitive world, termed 'concerted cultivation'. Singh (2004) also suggests that the 'mother-blame, brain-blame' debates, which exist in the management of ADHD, serve to allow the success of Ritalin (methylphenidate) to alleviate mothers' sense of blame and therefore reinforce the oppressive cultural ideology of the 'good mother.' Interestingly, some recent findings suggest fathers tend to resist using a medical framework to explain their child's behaviour (Chen, Seipp & Johnstone, 2008). However, they tend to be distant in discipline and parenting as conveyed in social discourses of 'fatherhood' and media representation (Lupton & Barkley, 1997).

The loss of extended families, breakdown in immediate families, and an increase in busy lives all indicate cultural influences, which might contribute to our understanding of the child in context (Timimi & Taylor, 2004). Bull and Whelan (2006) outline how parents within their study developed restricted perspectives of their child's 'ADHD' in which social factors, such as those described by Timimi and Taylor, were rarely

considered. Consequently, limiting parents' options in the management of perceived difficulties and creating an apparent necessity for medication (Bull & Whelan, 2006). This suggests that whilst social explanations of children's behaviour may be important they appear to be undervalued within ADHD practice and parental views.

Psychological models of understanding have also contributed to ADHD literature; however, remain limited in their application. Attachment theory has been utilised to explain 'ADHD' behaviours. Golding (2004) identified the ambivalent-resistant attachment style as contributing to attachment stories behind ADHD. Early attachment theory suggests all children require emotional security and comfort to form a secure attachment (Bowlby, 1982). Children who experience inconsistent and unpredictable environments are more likely to experience anxiety, use affect-based strategies for coping, including exaggerated displays of negative emotions, and develop behaviour which seeks the attention of caregivers; becoming loud, restless, and hyperactive. Such behaviours escalate when adults show disinterest. Clearly, Golding (2004) identified similarities between ambivalent-resistant attachment and those described as having ADHD, thus one alternative discourse for ADHD is that of a child in unpredictable environments in which caregivers are unresponsive and unavailable. Similarly, children in domestic violence situations are likely to experience anxiety around security and similar attachment behaviours are likely to surface (Vetere, 2004). Again, children who are exposed to abuse, neglect, or trauma will exhibit behaviours usually associated with ADHD (Myatt, 2004). This evidence suggests ADHD behaviours are manifestations of how children have learnt to interact with the world and adapt to their environment. This is further reinforced by findings that children diagnosed with ADHD can behave 'appropriately' in some situations and at the level to those considered 'normal' (Brown,

2004). Phillips (2005) states that occurrences of autistic behaviours are attempts at self-cure and damage limitation in the context of the child's traumatic separation from its mother. Phillips (2005) maintains that these behaviours, whilst culturally inappropriate, are understandable within the context they occur and what is required is an awareness of how behaviours, such as hyperactivity and inattentiveness, relate to the child's environment.

2.6 Current Practice

The National Institute of Health and Clinical Excellence (NICE) issued guidelines on the diagnosis and management of ADHD in children, young people and adults (NICE, 2009) and medication use for ADHD in children and adolescents (NICE, 2006). These guidelines recommend that diagnosis of ADHD should meet diagnostic criteria in DSM-IV or ICD-10 and that psychological, social or educational/occupation impairment should be present in two or more important settings. Such diagnostic processes should also include an assessment of the person's needs, coexisting conditions, social, familial and educational or occupational circumstances, including physical health and parent/carer mental health. Management guidelines highlight the need for parent-training/education programmes as the first-line treatment, behavioural interventions in the classroom and in the case of moderate levels of impairment parent training/ education programmes and/or cognitive behavioural/social skills training groups for the young person. For 'severe' impairment, the advocated first line treatment is the use of medication, such as methylphenidate. NICE identified the importance of a comprehensive programme of support, including psychological, educational, and social measures, alongside medication. They also emphasise the importance of person-centred care in order to allow people to make informed decisions about their care.

NICE guidelines claim to use the best available evidence to determine best practice. However, these guidelines have received criticism, primarily for a failure to provide data to support their recommendations for the use of medication and an absence of acknowledgement of the flaws in the American multimodal treatment study upon which they are based (Baldwin, 2000; Multimodal Treatment Study of ADHD Co-operative Group, 1999). These flaws include the randomised controlled trial not being placebo controlled or double blind (Breggin, 2001). Moreover, inadequacies in, and methodological challenges of, health technology appraisals for ADHD treatments have been identified (Griffin, Weatherley, Richardson & Drummond, 2008: Schlander, 2008a, 2008b). These include a lack of agreed measures for success and little or no evidence on long-term outcomes of treatments. In addition, Egger and Emde (2011) discuss how the current mental health classifications are imperfect and call for a developmental understanding within the diagnostic criteria. Yet despite the lack of support and apparent inconsistencies within research literature, the existence of NICE guidelines continues to suggest that a clear understanding of ADHD and its management does exist within clinical practice.

2.7 Medication

NICE guidance (2006) identifies the three main psychotropic medications commonly used for the treatment of ADHD in the UK. Methylphenidate and Dexamfetamine are stimulant medication and Atomoxetine is a selective noradrenaline reuptake inhibitor. These medications have been reported to have a beneficial effect in reducing children's inattentive behaviours; however, the exact way in which this is achieved is unclear.

The use of medication has been an issue of concern within professional and social arenas. Methylphenidate is a schedule 2 controlled drug belonging to the amphetamine

family and developed as a medication for ADHD. This is despite long histories of amphetamine-like prescriptions to adults that were considered too addictive, hazardous, and prone to misuse to be prescribed to under-eighteens. Baldwin (2000) suggested that pharmaceutical companies have specifically marketed methylphenidate within the child and adolescent population, which has resulted in over use in clinical practice.

Findings of a wide scale meta-analysis of randomised controlled trials of methylphenidate demonstrated short-term clinical effect in treatment of ADHD (Schachter, Pham, King, Langford & Moher, 2001). These effects did not remain beyond four weeks and inconsistencies within ratings scales, problems with side effects, and observed publication bias were cited. Questions have also been raised regarding the validity of results that indicated a reduction in clinical presentations. In addition, significant side effects of decreased appetite, insomnia, stomach aches, headaches, and dizziness were reported by parents and teachers but interestingly were underreported by those conducting the trials (Schachter, et al., 2001).

More recently, research into the efficacy of medication use for ADHD has focused on comparisons amongst recommended stimulants and contextual understandings of medication use (Faraone & Buitelaar, 2010; Leslie, Plemmons, Monn & Palinkas, 2007). A study into the effects of placebo drug treatments for ADHD found that both parents and children reported improvements in the perceived difficulties when prescribed placebo drug treatments. Full disclosure of the placebo and open label usage during treatments did not reduce the reported effectiveness. It was concluded that changes in parenting styles and behaviour might have contributed to the positive outcome (Sandler, Glesne & Geller, 2008).

Whilst medication is reported to be helpful in reducing behaviour associated with ADHD (Greenhill, Findling & Swanson, 1999; MTA cooperative group, 1999) problems with side effects and criticisms over the validity of these findings have been identified. It is becoming more widely documented that medication alone is unlikely to address the wider difficulties associated with ADHD, including learning, interpersonal relationships and self-esteem (Bates, 2009). However, an increase in prescription rates of medication for those diagnosed with ADHD following the issuing of the NICE guidance has been reported (Foreman, 2010).

2.8 Management approaches

In response to documented limitations of pharmacological treatments of ADHD and ethical considerations of medicating children and young people, research into psychological treatments for ADHD has emerged. NICE guidance suggests that parent-training/education groups and cognitive behaviour therapy or social skills training for children and young people either in a group setting or an individual basis should be offered as part of a comprehensive management approach (NICE, 2009).

Singh et al. (2010b) identified that mindfulness training for parents enhanced their children's compliance with instructions concluding that such approaches produced personal transformations in both parents and children. This is of interest when related to the perceived barriers to adherence to psychological recommendations, which Dreyer, O'Laughlin, Moore and Milan (2010) suggest are due to parental stresses.

Bimble (2009) reviews a number of possible behavioural approaches to ADHD and concludes that whilst such approaches are likely to prove useful, the current climate of

the ‘quick fix’ and expectations of treatment regimes may prevent professionals, parents, and young people from engaging with such approaches. Bimble further highlights that a consistency within the management of the child’s home and school environment and parental co-operation are paramount for successful outcomes in psychological management approaches to ADHD.

Problematic family functioning has been seen to impact on characteristics of ADHD (Deault, 2010; Johnstone & Mash, 2001) which has implications for management. In addition, parents’ and professionals perceptions of ADHD are seen to directly impact on support offered to families (Dennis, Monica, Johnson, Brooks & Humbi et. al., 2010).

In reviewing the literature regarding treatment options for ADHD it is clear that limited evidence exists to supports the effectiveness of psychotropic medications and research into alternative treatment options is limited. Kenny and Blew (2006) suggest that a holistic, culturally sensitive, and family focused approach is required to empower the child and family to manage ADHD successfully. However, limited research is available in which to inform current practice and foster such approaches.

2.9 Deconstructing ADHD practice

Research indicates that constructs of ADHD are based on dominant medical discourses, which consequently influences children’s self-identity (Brady, 2005). Brady suggested that this requires a need to appreciate the individual’s experience and move towards a sociological and psychological analysis. Singh (2007) has also suggested that the notion of ADHD as a medical disorder, which originates within the individual, has shown to impact on children’s reports of their self-concept. Consequently, children taking

prescribed methylphenidate believe a core dimension of their selves to be 'bad' (Singh, 2007). In an attempt to engage further with individual experiences of medication use, Singh et. al., (2010a) concluded that young people generally reported that medication led to a reduction in impairments. Therefore, concluding that social stigma is associated with the impairments themselves rather than a by-product of the medication, which had been suggested previously (Singh, 2007). Parent's dilemmas regarding the use of medication also reflect this; describing a balancing act between the desirable and undesirable effects medication produces (Hansen & Hansen, 2006).

A study of parenting experiences of children diagnosed with ADHD in Korea highlighted the social and psychological processes which influence families and identified a parental need to 'establish normalcy' within their child (Oh & Parks, 2007). A process of having to overcome difficulties in family life was evident in these experiences and similar challenges within the home environment have been identified in studies of American and Canadian families (Firmin & Phillips, 2009). A study of African American families outlined how parents reach a decision to seek care for their child's behaviour and identified stories of seeking resolution and pressures to conform as pertinent to this decision (Reis et. al, 2007).

As a need for a greater understanding of ADHD and current practice has emerged, some psychiatrists and psychologists have written about their clinical practice, which focus on social and psychological models of ADHD. Timimi (2004) describes modernist and postmodernist perspectives where he acknowledges his 'expert perspective' whilst exploring alternative narratives and deconstructing the medical notion of behavioural problems. Cobner (2004) describes her practice as one that attempts to deconstruct ADHD and explore alternative narratives, which she feels helps to challenge parents'

understandings of their children's difficulties and places them within context. Others have attempted to place the child's problems within their social context through behaviour programmes that change how caregivers and systems around the child respond to children's behaviour (Daley, Creed, Xanthopoulos & Brown, 2007; Woodhouse, 2004). It is therefore, argued that social and psychological models of ADHD may help reveal meaningful understandings of the processes involved in the current diagnosis and management of ADHD. The application of such models, however, appears to have been limited by an over reliance on the medical model. Therefore, research within a social constructionist framework may offer further insight into this phenomenon.

2.10 Conclusions

The debates over ADHD practice are clearly embedded within a wider cultural acceptance of dominant medical discourses, which have drawn upon positivist versions of science. This has been contested in relation to psychiatric diagnosis in general, as well as specifically that of ADHD. Nevertheless, positivist discourses continue to be intrinsic to our economic, legal, social, and health service structure. Furthermore, such medical discourses may function to alleviate parents' distress and feelings of blame, which could alternatively originate in social explanations. It seems that both professionals and parents continue to adopt a perspective of ADHD that neglects contributions from the social and environment context. Furthermore, evidence for the effectiveness of current practice remains limited.

3 Research rationale and aims

The current review calls for a continued shift in ADHD research towards an understanding of children's behaviour within a social, cultural, and environmental context. In order to inform current practice a more robust base of research is required, which takes into account the individual experiences arising from current practice. Counselling Psychology is well placed to understand the meanings, beliefs, context, and processes that are constructed both within and between people, which in turn affect the psychological wellbeing of children and their families. Consequently, research, which adopts a human science perspective, should contribute to ADHD literature in a way that is of interest to Counselling Psychologists.

This research aims to engage with the experiences of professionals, parents, and children in order to develop a rich understanding of the current diagnosis and management of ADHD. The research also aimed to adopt a social constructionist framework in an attempt to move away from positivist approaches to ADHD towards an understanding of how social, cultural, and environmental contexts, construct meaning of the perceived problem.

3.1 Contextual Considerations of the research aims

As a trainee Counselling Psychologist and through my employment as a Child and Adolescent Mental Health Worker within the National Health Service (NHS) I have an interest in the area of ADHD and the management of such presentations. My interest in meaningful understandings of 'ADHD' stems from the humanistic philosophical underpinning of my training and an emphasis on the therapeutic process. Therefore, the decision to engage with experiences of ADHD is also due to a personal and professional

desire to foster positive outcomes for children and young people. When engaging with children, young people, and families I seek to adopt a systemic approach that seeks to place the presenting difficulties within their context (Hedges, 2005).

In reviewing past and present literature on ADHD it is clear that it presents as a major concern within health care services. NICE guidelines outline recommendations for the organisation of care for ADHD (NICE, 2009). This focuses upon a stepped model of care and the four-tier strategic framework of Child and Adolescent Mental Health Services (Health Advisory Report, 1995). An overview of this framework is included in Appendix 2 to orientate the reader to the context, an overview of how ADHD care pathways relate to this framework is provided by NICE (2009, p. 134). It was due to the prominence of Child and Adolescent Mental Health Services (CAMHS) in relation to ADHD that the current research sought access to a NHS Tier 3 CAMHS service.

3.2 Ethical Considerations

A number of ethical dimensions were considered throughout the research process. This included attention to, ethical issues around research with children and young people (Alderson & Morrow, 2004), the Good Practice Guidelines for the conduct of Psychological Research within the NHS (BPS, 2005) and the Code of Conduct and Ethical Guidelines (BPS, 2006).

Throughout the research process, I was aware of controversies over the use of language in relation to children and young people. The term ‘young people’ is used here to refer to children under the age of eighteen years as it reflects terminology employed within the services involved in the study. Throughout the research design and recruitment process an awareness of, and consideration for, children who live with non-parental

carers and adults who have parental responsibility, was present. However, as all the adults and young people involved in the study were from families where both biological parents were present, the term ‘parent’ is used throughout this report.

Whilst conducting the research I worked within a service that worked in liaison with those involved in the study, however, did not have clinical responsibility for any of the participants who took part in the study. I considered that my professional experience would be valuable in effectively conducting research with children in a sensitive manner and in responding to emotional distress (Coyle, 1998). I also considered that participants might view the interview as an extension of their current treatment or therapy. Therefore, at the recruitment stage I informed individuals that the interviews would not be therapeutic visits.

In considering issues around informed consent with children, I adopted the view that parents have responsibility rather than rights over their child and that this reduces as the child matures to reflect their individual level of autonomy. Therefore, when recruiting children under 16 years of age I asked parents to provide assent. They were also encouraged to support their child in making a decision. Therefore, consent was requested from both parent and child regardless of age. I paid further careful consideration to issues of informed consent with participants over 16 years of age, freedom and willingness to participate, confidentiality, and the potential impact of the research. Throughout the write up I highlight the ways in which I addressed these issues. The study was approved by The University of Wolverhampton School of Applied Sciences and the NHS Local Research Ethics Committee (See Appendix 3 & 4).

4 Method

Clinical guidelines for the diagnosis and management of ADHD have been developed. However, a review of research suggests that there continues to be controversy and disagreement between understandings of ADHD. In addition, evidence for the effectiveness of management approaches has been limited. It has been suggested that ADHD could also be viewed within its social context as a cultural construct. The current study was developed within a qualitative paradigm and social constructionist framework. In addition, grounded theory methods were used to achieve the research aims. The following section describes the methodology employed within the current research.

4.1 Qualitative Paradigm

Qualitative research is concerned with meaning and individual experiences rather than identification of cause-effect relationships (Willig, 2001). In contrast, much of the existing research into ADHD has emerged from positivist approaches and hypothetico-deductive methods. In line with its aims the current study adopted a qualitative approach to explore lived experiences of ADHD.

Qualitative methods are concerned with engaging in exploration, description, and interpretation of personal and social experiences. Therefore, a range of data collection and analysis techniques can be adopted which allow the researcher to take a holistic approach to the research material and engage with meaning and context (Hayes, 1998). Grounded theory methodology goes beyond description of experience, and facilitates a process of discovery and theory generation (Pidgeon & Henwood, 1997). In addition, it offers a comprehensive framework for inductively building an emerging theory through

systematic data collection and analysis (Strauss & Corbin, 1998). This study adopted grounded theory methodology to explore meaning within individual experiences of ADHD and develop theory relating to current diagnosis and management. Whilst Strauss and Corbin (1994) have clearly stated that, they believe that truth "is enacted" (p. 279) it has been noted that they do not directly identify their ontological position (Mills, Bonner & Francis, 2006). I discuss the importance of this below.

4.2 Conceptual Framework

The current study aimed to move away from positivist investigations of ADHD. Positivism continues to form the philosophical underpinning of mainstream natural science. This maintains the belief that it is possible to obtain objective knowledge through observation. In addition, hypothetico-deductive methods are driven by attempts to falsify exiting hypotheses. Such approaches stand within a realist ontology and assume the stance that a 'truth' exists (Willig, 2001). In contrast, there appears to be an existing body of literature, which suggests that different views of ADHD exist.

Madill, Jordan and Shirley (2000) identify three epistemological positions within qualitative research approaches, termed, realist, contextual constructionist, and radical constructionist. The philosophical underpinnings of a research approach reveal important assumptions about the method of inquiry and the role of the researcher. Willig (2001) outlines the continuum between realist and relativist epistemologies against six qualitative methods (see Figure 1). The current research method is concerned with both the researcher's and the participants' interpretation of the social context and attempts to move away from realist observations. Therefore, a contextual constructionist approach to grounded theory was selected.

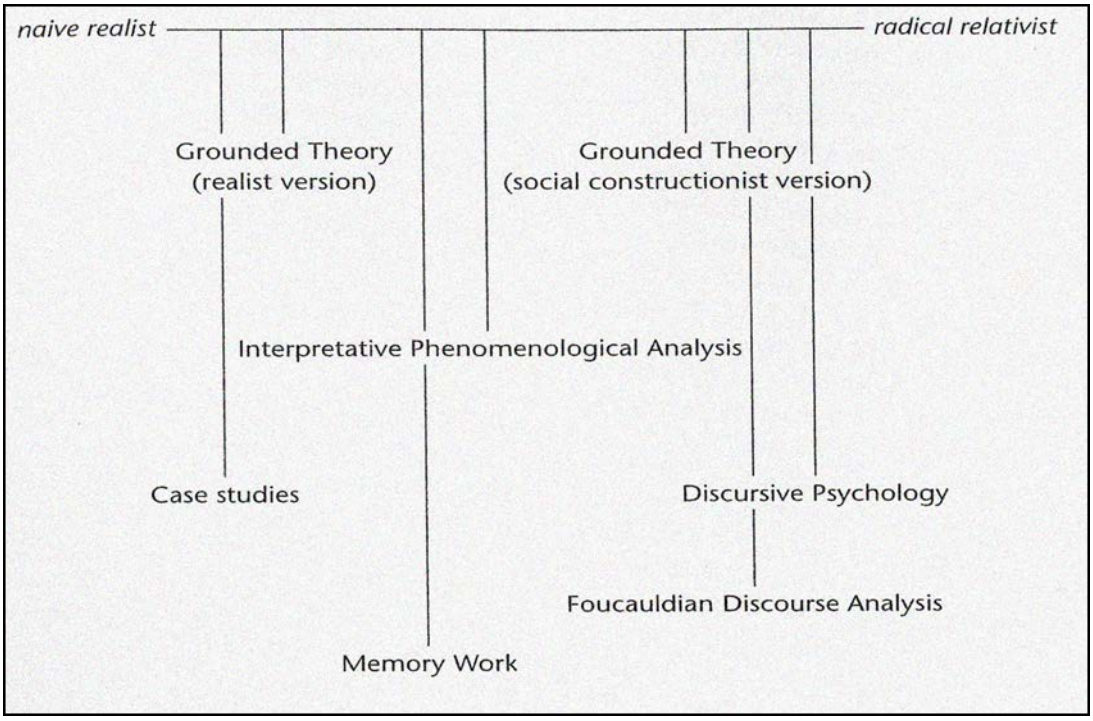

Figure 1. Epistemological positions and methodological approaches (adapted from Willig, 2001).

From a constructionist position, social processes are the foundation of reality (Gergen, 1985). Social constructionism suggests that social reality is interpreted through culture, history and language (Burr, 2003). Knowledge is transferred between individuals through discourse which must be interpreted within the social context it is used. Gee (1992) proposes that discourse incorporates human thought, action, and language within a cultural framework. Influences on the social constructionist position originate in symbolic interactionism. Fundamental to symbolic interactionism is the notion that individuals learn to interact with others by assimilating a shared system of symbolic representation (Mead, 1934). This suggests that multiple interpretations of the social world exist as meaning and is socially negotiated and mediated. Therefore, shared knowledge and understanding can be revealed by engagement with social interactions, which extend beyond the individual.

Constructivist versions of grounded theory have built upon elements of interpretive and constructionist inquiry. This ensures that observations are grounded within their context. Constructivism, whilst closely related to social constructionism, relates to the individual's interpretation of socially constructed artefacts. Charmaz (2006) outlines an approach to grounded theory which utilises a constructivist approach by exploring how individual's view their experiences. In addition, Charmaz (2006) argued that close interaction between the researcher and data constructs categories of shared understanding. The current study adopted a methodological process that identified data and analysis as created from these shared understandings.

4.3 Design

4.3.1 Participants

Within the current study, data was collected from multiple participant groups. It was felt that professionals, parents, and young people are ideally placed to offer a rich understanding of ADHD. Therefore, these participant groups were chosen prior to commencing data collection due to their theoretical significance and the potential to engage with different experiences that would create a meaningful whole.

For the purpose of research within the NHS an initial sample size was required. Patton (1990) suggests that validity within qualitative research is concerned with information richness and not sample size. Within a grounded theory approach, richness is likely to develop through adequate sample sizes and theoretical sampling techniques. With this mind, a maximum sample size of twelve was set prior to commencing the study. This allowed some flexibility in theoretical sampling whilst ensuring that the data collected was manageable within the scope of the study.

The study used an initial purposive sampling approach (Holloway, 1997) to select early research participants significant to the aims. Subsequently a snowball sampling approach identified further interviewees from initial participants.

4.3.2 Recruitment of participants

The study took place within two separate services. Initially within the National Health Service at a Tier 3 CAMH service. In addition, further research took place within a third sector provider service in the same area. The inclusion criteria are outlined in Table 1. In order to identify possible participants who may be relevant to the research aims I developed an understanding of the service in which the research took place, the roles of the professionals within these services, and the families who use the services. This was achieved by seeking information and advice prior to the recruitment process. The NHS trust's research and development department requested that this be carried out by a Psychiatrist with expertise in ADHD.

Table 1. Inclusion criteria for the recruitment of participants.

Participant group	Inclusion criteria
Professional	1) Registered with a professional body, e.g. BACP, BPS. 2) Employed within one of the identified services. 3) Direct clinical experience of ADHD.
Children and young people	1) Children and young people over the age of eight. 2) Have received a diagnosis of ADHD. 3) Under the care of one of the identified services.
Parent/ Carer	1) Parental responsibility for a child diagnosed with ADHD. 2) Parental responsibility for a child who is under the care of one of the identified services.

The minimum age for participants was selected due to the average age of diagnosis being eight years of age. In addition, it was felt that children above the age of eight are likely to have reached a level of cognitive and emotional development sufficient for the purpose of the study (Grieg, Taylor & Mackay, 2007).

Initially, professionals who met the inclusion criteria were identified and invited to participate in the research. They were then asked to invite service users and parent/carers currently on their caseload who met the inclusion criteria. I also attended a parent support group at the third sector provider service following a snowball sampling approach.

4.3.3 Description of participants

The study recruited nine participants, consisting of four professionals, two young people, and three parents. Data collection was discontinued after nine interviews due to the richness of the data already collected and the limitations of the scope of the study.

The two young people interviewed were both male, aged ten and eighteen years old and received a diagnosis of ADHD at the age of eight and ten respectively. One of the young people interviewed described being prescribed methylphenidate and the other described taking ‘a 10 and a 5 tablet’ that was confirmed by his parent as being Concerta 36mg and Equasym 10mg. One the young people also had a diagnosis of obsessive compulsive disorder (OCD).

All the parents interviewed were female and aged between thirty-five and thirty-eight. All their children were aged between six and seven at the time of diagnosis and were prescribed stimulant medications including, Concerta XL 18 mg, Methylphenidate

10mg, Concerta 36 mg and Equasym 10mg. One of the children was also prescribed 'Melatonin' to aid sleep. Of the parents interviewed, one had a female child with ADHD and the remaining two had male children, aged between six and ten at the time of the interviews. One of the parents' children was also involved in the study and interviewed separately to their parent. Two of the parents were identified through the third sector service however were also known to the Tier 3 CAMH service. Out of all the parents and young people involved in the study only one family described receiving support other than medication, this was Cognitive Behavioural Therapy and was described as being for the treatment of OCD.

All four professionals were female. One professional was a trained Social Worker, one as a Psychiatrist and two were qualified Teachers. They all had experience of working with children and families with ADHD for between five and nine years.

4.3.4 Data Collection

A semi-structured interview was developed (see Appendix 5). The interview questions and techniques to data collection remained flexible in response to the developmental age of the child (Grieg, Taylor & Mackay, 2007). One of the children interviewed chose to use art materials to help communicate their experience. Silverman (2002) suggests that interviews do not produce prior realities and remain contextual in nature when negotiated between participant and researcher. The interviews in the current research followed a conversational style that allowed the interviewer to pursue themes within the interview and allow the interviewee to identify themes pertinent to their individual experience. The interviews lasted between 50 and 70 minutes. Participants completed a short demographic questionnaire, which provided relevant background used within the analytical process to provide a contextual understanding of the data (see Appendix 6).

Grounded theory methodology adopts a theoretical sampling approach in which data significant to the research question is sought (Charmaz, 2006). Theoretical sampling within this study allowed developments and changes to be made within the data collection phase. For example, flexibility in the semi-structured interviews was utilised in order to focus on experiences relevant to emerging codes and categories.

4.4 Procedure

Potential participants were invited to participate in the study by letter, presented in person by either a professional within the service or myself (see Appendix 7). An information sheet explaining the nature and rationale of the research, confidentiality issues, anonymity and the right to withdraw was enclosed (see Appendix 8). A reply slip and pre-paid envelope was also enclosed to indicate their willingness to participate and provide contact details for the researcher to arrange an interview time (see Appendix 9). A telephone number was available to the participants if they had any queries about the study. Members of staff working within the services where the research took place were asked to direct any queries to me on the telephone number provided. Willing participants were invited to an interview at their convenience at CAMHS.

Prior to the interview participants were reminded of their rights in the study and asked to sign a consent form (see Appendix 10). Interviews were digitally recorded and subsequently transcribed. Transcripts were, labelled and line numbered, and details made anonymous to protect the identity of the participants. All materials were kept securely and in keeping with respect for confidentiality.

In line with grounded theory methodology, data collection and analysis ran concurrently. Charmaz (2003) suggests that theoretical sampling is a specific technique used to develop emerging theoretical categories and should be followed until saturation, when no new data emerges. The data collection process was guided by early coding and was sensitive to emerging categories. Throughout the data collection process the interviewer remained attuned to participant's perceptions, differences in power, histories, gender and culture and as such aimed to document what is happening throughout the research process from a contextual constructionist position. Grounded theory interviewing allows the researcher to notice and pursue themes in interviews as well returning to the field to gather and focus data. Furthermore, reflexivity of how and what data is collected helps to contextually place the data and construct meaning (Charmaz, 2006). Self-reflective journals and memo writing therefore offer insight into the grounded theory process and document the analytical processes.

4.5 Analytical strategy

Once data was collected and transcribed, it was analysed using a contextual constructionist version of grounded theory (Charmaz, 2006; Pidgeon & Henwood, 1997). Charmaz (2006) suggested that 'like any container into which different content can be poured, researchers can use basic grounded theory guidelines such as coding, memo-writing and sampling for theory development, and comparative methods are, in many ways neutral' (p. 9). This illustrates the importance of flexibility within constructionist versions of grounded theory in order to allow the emergence of theory and an avoidance of 'forcing' theory through prescriptive data analysis methods (Kelle, 2005). Debates around emergence vs. forcing in grounded theory generation stem from the differences in epistemological positions from which the different versions of

grounded theory originate. As such, constructionist analytical procedures remain close to the construction of meaning between participant and researcher. In contrast, inductive methods of grounded theory have been argued to force preconceived conceptual descriptions upon data (Duchscher & Morgan, 2004).

During the analytical process, units of data are given concept labels that are progressively abstracted and categorised (Glaser & Strauss, 1967). Initial stages of the data analysis phase involved open coding procedures. The current research made use of line-by-line coding in which the researcher remained close to the data and labelled every line according to the actions present. For example, the line "and I think as I have got more experienced" (Professional interview 1, Line 14) was coded as 'developing experience.'

The second stage of open coding was to label the data incident to incident. This involved looking for incidents in the data and labelling them according to the significance of its content. For example, when parent 1 is describing her decisions to medicate her child (Line 590-601) the code 'medication' was selected. In-vivo coding was also used selectively to refer to participants' special terms in an attempt to preserve meaning, for example, 'raise the red flags' (Professional 3: 543) was used to describe the identification of problems. The process of open coding allowed early, provisional codes to form which remained grounded in data. A constant comparative method was used which compared the following elements 1) data from individuals, 2) individual data within own data narrative 3) incidents with incidents and 4) categories with categories (Charmaz, 2003). This process involved moving back and forth between the data transcripts and identifying similarities and differences between the codes and emerging categories. By using these methods the researcher stayed close to the data and

allowed theory to build from the ground up. This ensured a good fit and relevance to the data collected.

The second stage of the data analysis phase was the use of focused coding methods. Charmaz (2003) described the purpose of focused coding as moving analysis forward in order to establish the content of emerging theory. This requires an evaluation and clarification of the categories and relationships between them. In addition, cases, which do not fit the emerging categories, are searched for in an attempt to capture the full complexity of the data (Willig, 2001). Within the current research, this involved identifying the most significant early codes and grouping relevant or similar codes to compare their analytical strength and thus make decisions about the adequacy of them. At this stage, concepts began to emerge and new lines of analysis were followed. The process of coding fragmented data that was then reorganised according to the emerging categories. This involved moving between interviews and observations and comparing experiences, actions, and interpretations to piece the data back together in an analytically meaningful way. For example, the quote "being told that can have you know quite vast emotional difficulties about crying for that normal child" (Parent 2: 243) was placed in the category, 'emotional conflict'. This was compared to other interviews and experiences of 'emotional conflict' until the category was saturated.

Data ordering was also utilised to explore the chronology of events and examine the processes within the data (Pandit, 1996). This involved placing key events from the data in a sequence to develop an understanding of the processes involved in the diagnosis and management of ADHD. A chronology was documented which commenced with identification of difficulties and moved through diagnosis and eventually management.

This provided an important resource for later analysis in which relationships between categories were explored.

Strauss and Corbin (1998) advocate axial coding as a third coding method, which provides a paradigm for systematically linking the categories together in complex ways. However, the use of the formal structure of axial coding has been criticised for its inconsistencies with the notion of theory construction. Charmaz (2003) argues that axial coding casts a technological overlay on the data and questions how the process differs from careful comparison. It was felt within this study that such an approach is overly rigid. Therefore, theoretical coding was implemented in order to conceptualise, integrate categories, and make links between them. Glaser (1992) suggested that theoretical coding precludes the need for axial coding as it 'weaves the fractured story back together' (p.72).

Within the current research, theoretical coding involved mapping and diagramming the categories and subcategories. This generated an explicit story line of the data. The emergence of a storyline became the descriptive narrative in which the categories and subcategories were related. The story line in the current study described a process of '*investing in ADHD*' highlighting the core phenomenon of the processes involved in the diagnosis and management of ADHD. As described earlier I refrained from applying a paradigm model or explicit framework (also known as axial coding) to the data so as not to restrict the construction of theory. Consistent with a constructionist stance the data analysis and subsequently the story line within this study aimed to explain how and why participants constructed meanings of children's behaviour and the actions they take to manage this. Therefore, '*investing in ADHD*' was seen as a central category.

Subsequent categories and subcategories were related to the central category in systematic ways.

Finally, the stage of writing and reporting the analysis can be seen as part of a constructionist analytical procedure within grounded theory. Charmaz (2006) recognises how writing can provide context for theory development as links are made with existing theory. Report writing also provides an arena to examine the presentation of categories and consider them in a critical manner. Within this study the analytical process was not complete until the published version was presented.

5. Analysis and Discussion

The following section presents the analysis of experiences of the diagnosis and management of ADHD within the current study. Initially, the categories and subcategories, which developed through the analytical process, are identified in Figure 2. An in-depth explanation, of each of the categories and subcategories, using illustrations from the data, is then provided. These illustrations are labelled according to the participant from which they originated and the line number within the transcript as it was felt that this provided a voice to the underlying meaning. A deconstruction of each category is also explored to reflect the constructivist grounded theory methods employed and the multiple meanings within the data. A diagrammatical representation of the categories and subcategories is presented in Figure 3. This model conceptualises the categories and subcategories that were formed throughout the research process. The emergent 'story line' is then presented which provides a descriptive overview of the interpretation of the conceptual model.

Following a presentation and exploration of the analysis, these findings are also discussed as they relate to existing theory and research. The limitations of the current study and its relevance to further practice are also considered. Finally, implications for future research are offered.

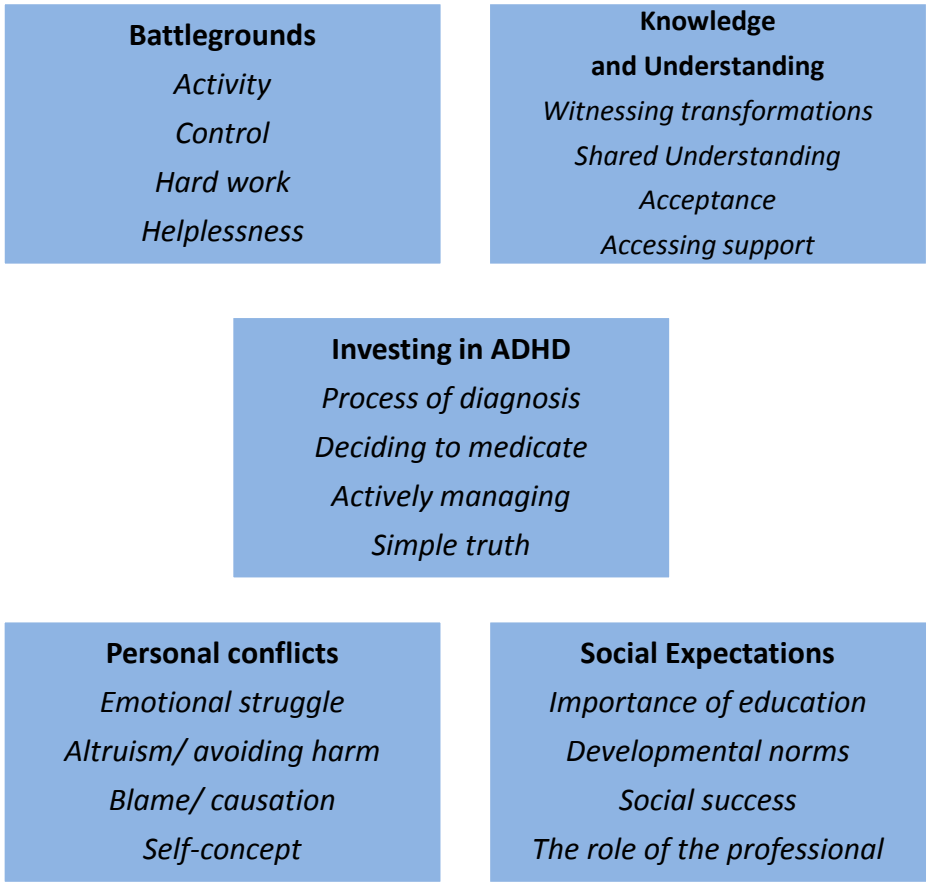

Figure 2. Identification of categories and subcategories

5.1 Description and exploration of categories and subcategories

5.1.1 Battlegrounds

The category '*battlegrounds*' encapsulates the strong sense of having to fight battles which was identified throughout the participant's experiences. Parents and professionals identified children's *activity* levels as problematic and the children were perceived as out of *control* "actually the truth is that if a child is so out of control" (Professional 1: 60). As adults attempted to take *control* they described how the energy this required was exhausting "he's repeated to the point where I've just lost my rag with him because mentally I've not been able to cope" (Parent 1: 122).

The following quotation illustrates a parent's sense of battling with their child and their tendency to make comparisons of their child as 'different' to others:

> "I just think they are a lot more demanding, a child without ADHD, you can reason with them or you can tell them we're doing this, and they will say, ok, mum's doing this, well this what my perception is, but with an ADHD [child] if they have got something different in mind, they want to do that different thing so you have to find ways of getting round what to do" (Parent 2: 919).

Parents, professionals, and children identified the *hard work* and investment of energy that gaining *control* of *activity* takes. Without *control* a position of *helplessness* appeared to be formed "I can't stop that I can't change him" (Parent 1: 1308).

Young people revealed a sense of battling to *control* their own *activity* levels "Cos I can't help it I want to get rid of it" (CYP 1: 173). These battles appeared to lead to a sense of *helplessness* in which they reluctantly surrendered to the need for extra support "I would rather not have support….because I don't wanna be seen as thick" (CYP2: 483).

Activity

The perception of children's *activity* as problematic was positioned as a subcategory within *Battlegrounds.* Children were portrayed as engaging in non- stop *activity*. For example, "its non-stop questing and he will be like that from when he gets up in the morning until the minute he goes to bed" (Parent 1: 13). This *activity* was deemed beyond acceptable levels. Throughout the accounts children's behaviour was

described as; trivial “obviously there are times when you think oh for goodness sake [name] that is ridiculous” (Parent 1: 161), impulsive “you didn’t know what he’d do next” (Parent 2: 157), or volatile “and they become physical as well especially as they get to adolescence” (Professional 3: 333).

Parents described experiencing difficulties with a range of ‘ADHD’ behaviours, such as, lack of sleep, constant questioning, lack of compliance and demand for attention. For example, “she just wants attention and you are walking around at night times and she is pulling all the time and she is continually asking” (Parent3: 937). These difficulties were portrayed as affecting those around them, causing disruption and stress within families, and were used to define the child with ADHD as ‘different’. The sheer level of *activity* and the perception of their child as ‘different’ appeared to lead parents and professionals to search for an understanding of the child’s behaviour. For example, “The flags are raised, the red flags, nursery says to mum that you know he is boisterous” (Professional 3: 543).

Control

The perceived need to ‘calm the situation down’ was related to a positioned need to gain *control* of children or for children to learn to *control* or ‘regulate’ their own behaviour. For example, “it can them calm the situation down for you to be able to address the underlying issues” (Professional 1: 56). Without *control* there appeared to be no hope in alleviating the problems. For example, “you know just having no real social opportunities and parents who don’t use any sort of boundaries or sanctions so it is a really chaotic crazy life for these kids” (Professional 1: 498).

One professional described a battle between gaining *control* of the child for their "personal safety" and the child's desire to be a "free agent" (Professional 3: 309). She also described her perceived role in supporting a young person to learn to "stop and think" (Professional3: 339) this exists within a context of needing children to *control* their own behaviour in order to function within acceptable social limits. For example, another professional indicated that by gaining *control* young people will "become full and promising members of society" (Professional 4: 247). At times, the need for *control* was directed towards parents. For example, one professional described how she would support a parent to implement rules and boundaries with the aim of helping them gain *control* of a situation (Professional 4: 315).

During the interviews, young people also communicated attempts to remain 'in control.' One young person perceived his younger self to have been "out of control" (CYP2: 596) and felt that by locating the problem within his brain he had lacked the ability to *control* himself "it isn't me what can't control myself it is something what is actually doing it to me" (CYP2: 413). However, he had learned to gain *control* through a combination of maturing, medication, and actively managing his energy levels. Whilst this young person clearly articulated his ability to gain *control* of his behaviour, generally such attempts required support from professionals outside the family. Parents identified a battle between coping with *activity* and the sheer *hard work* required to *control* the situation.

Hard work

Hard work was identified as a sub category within *Battlegrounds,* which illustrates the magnitude of the emotional, psychological, physical, and temporal resources that

are required once a child has been identified as over active and/or inattentive. For example, “it’s hard to explain sometimes when I when I’m like I’ll speak to mum or I’ll speak to my sister on the phone and I’ll say I can’t tell you why he’s done my head in buts it’s just done my head in and he’s just hard work” (Parent 1: 831). She goes on to explain, “I got to the point where I kept crying and I had a nervous feeling all the time” (Parent 1: 852) which resulted in her “going on tablets”. Another parent described that “the doctor told me, he said you’re just exhausted you know, you, you need a break” (Parent 3: 400).

The young people interviewed also identified the *hard work* required in trying to manage their perceived difficulties. For example, “I get really frustrated I can’t help my anger” (CYP 1: 99) and when describing activities which demand attention “it’s much harder when it is isn’t physically moving about” (CYP 2: 225).

At times, the professionals appeared to struggle with limited resources that made perceived problems harder to manage. For example, “you’ve got a shortage of staff and big caseloads that makes it rather hard” (Professional 2: 106). They identified some of these struggles as stemming from challenges within the wider society. For example, in the media, “it must be awful to have your child on medication and then read a headline saying children have been drugged by amphetamines and then dying on medication so that can be a challenge” (Professional 1: 188). These challenges also stemmed from within family and educational settings. For example, “there are always the handful who are really challenging despite all the interventions so they’re the ones where I might be going into school more regularly to discuss” (Professional 1: 321). The extent of the *hard work* involved in dealing with ADHD was seen to lead to a sense of *helplessness*.

Helplessness

Often futile attempts to gain *control* of the difficulties appeared to create a sense of *helplessness* in the experiences of ADHD. For example, one parent stated "you're sick of hearing that y'know and it does, like whatever, like I can't do anything at home when it happened at school six hours earlier " (Parent 2: 278). Parent 3 described her sense of *helplessness* at not getting the support she was searching for "but it doesn't help us in the least and she let us walk out with nothing" (L356). This extract also illustrates parents beliefs that medical professional can explain their child's perceived differences, consequently placing the parent in a position of *Helplessness*.

The term 'behaviour difficulties' was often used to describe children's behaviour; however, this label appeared to contribute to the state of *helplessness* voiced in accounts. For example, "behavioural difficulties that is not helpful, you're just gonna think he's the little swine that you know won't behave" (Professional 2: 612). It appeared that this label served to locate the problem within the child or parent. In doing, so there appeared to no explanations or resolution to the problem, which consequently created a state of helplessness.

Professionals also identified feeling disempowered when faced with challenges over diagnosis. For example, one professional communicated a sense of frustration that "this teacher is very much wanting to convince me that the child hasn't got ADHD" (Professional 1: 140). This reduced her perceived ability to help, for example, "it does affect some of my patients because you know a lot of parents come in and they question the fact that they are on medication and there are a few who have stopped it

erm so it can challenge you know you're treatment of patients" (Professional 1: 182). Awareness of conflicting opinions regarding medication appeared to lead to ambivalence. For example, "you just don't know which way to turn with it" (Parent 1: 477). Therefore, the construct of ADHD as a medical diagnosis appeared to be maintained by descriptions of *helplessness* when possible alternative explanations are considered.

Deconstructing '*Battlegrounds*'

It was interesting to note that the construction of *battlegrounds* came predominantly from parent's perceptions of their child and was articulated in terms of how they believed children should behave. It could be suggested that parents constructed the *battlegrounds* of ADHD in terms of the constructs of 'appropriate' and 'inappropriate' behaviour. The perceived level of 'demand' of the child's behaviour (labelled '*activity*' and '*hard work*') contributed to a battle, which was predominantly with the child. This draws upon a discourse of 'abnormality', which can be seen to be located within a medical discourse. Thus, the '*battlegrounds*' in this study held implicit meaning for the parent, the professional, and the child. Subsequently, it appears that parents and professionals felt required to attempt to gain '*control*' over the child and their '*activity*'. It appears that in order to achieve and maintain this positioning those interviewed engaged in a great deal of rhetorical work, this was interpreted through expressions of '*hard work*' and '*helplessness*'.

In addition, discourses of 'normal' and 'abnormal' parental pressures were drawn upon. This suggests that the diagnosis performs important functions. For example, it may have served to resist a construction of either parent or child as inadequate. Furthermore, constructing the battle as a worthwhile struggle may also serve to

maintain professional and parental concern for the child, which further placed the difficulties within a medicalised construct, termed within this study '*investing in ADHD*.' The same discourses are taken-up by the young people, perhaps adding support to the notion that alternative ways of framing the experiences appear to offer less meaning and be more to the detriment of the participants.

5.1.2 Knowledge and Understanding

The terms *knowledge and understanding* encompass the process of establishing the 'facts' and 'truth' about the difficulties children, parents, and professionals were faced with. All the participants expressed benefits in finding meaning in the identified problems with children's behaviour. For example, "ensuring that they've got a knowledge about what it is" (Professional 2: 407). Professionals developed a sense of understanding though their training and clinical experience. For example, "I learnt how to do that as part of my training" (Professional 1: 610).

A search for *knowledge and understanding* by parents was also present throughout the accounts and it appeared that the health service was seen to offer this. For example, "right if that's her professional judgement and that's what she thinks then that's fine so I got him straight to the doctors" (Parent 1: 264). This position allowed families to move forward from *battlegrounds* to *access support* "someone keeps telling me if you go there [ADHD parenting group] you will understand a lot more on how she works and what is going on" (Parent 3: 1021).

Children's perceived *knowledge and understanding* appeared to create a sense of *control* over the battles. For example, "erm well it felt better because then it is off my

mind that I know what kind of erm… a medical problem I've got… I know what I've got then" (CYP 2: 407). In contrast, 'not knowing' contributed to positions of *helplessness,* which appeared to serve to maintain a search for *understanding.* Descriptions of *witnessing transformations* and creating *shared understandings* helped those interviewed to feel they could move forward. This required them to *accept* their child's difficulties as a diagnosable disorder and consequently *access support*.

Witnessing Transformations

Professionals described experiences of rescuing families from awful situations, minimising failures, immediate results of medications and overall improvements in functioning. These descriptions appeared to give professionals the confidence to 'believe' in their practice and appeared to construct and maintain a view of their role as 'helper'. For example, "I suppose having been here now for six years I have seen children you know start high school and then leave with their GCSE's, now you get more satisfaction of actually seeing, you know, the real benefits of treating ADHD" (Professional 1: 27). In addition, "we have been able to see some of those awful situations reverse" (Professional 1: 32). Medication was portrayed as having a major role in these *transformations* and this was articulated to parents. For example, "I would always be very open with my views of the difficulties of not medicating" (Professional 1: 202). Therefore, a sense of hope that problems could be reduced was created through the reporting of successful *transformations*. This influenced parent's decisions in how to deal with the 'problem'. For example, "you wanted him to go on it because you knew it was better for him" (Parent 1: 463).

Parents also engaged in stories of *witnessing transformations* when their children commenced medication. For example, “So it just shows you how good that medication is ‘cos they could see straight away” (Parent 1: 1447). The young people interviewed also reported experiences of *transformations* after receiving a diagnosis and medication. For example, “So my spellings came along a lot more and stuff improved, my concentration improved my workload improved, my work level, so it was much easier yeah and my grades” (CYP 2: 671).

Shared Understanding

Professional’s described experiences of working together with families that gave them a sense of understanding families and their problems. They described how they then passed their own understanding of ADHD onto others. For example, “I got a sort of series of leaflets that I send to school when a child is first diagnosed with ADHD” (Professional 1: 302). Having written information that reflected their narrative of the problem seemed important. This appeared to, create a sense of agreement in what ‘ADHD’ is, and help those involved to feel they are working together to help children and families. For example, “so they must understand and they don’t and this is where the conflict occurs” (Professional 4: 129). Some professionals described a sense of having a personal understanding of the difficulties families face “look I know what you are going through I’ve been through it” (Professional 4: 355). This appeared to maintain the view that the diagnosis of ‘ADHD’ is an adequate description of the perceived problem.

Sharing experiences and feeling understood was important throughout the experiences of ADHD. For example, “it is good meeting other parents who have

similar situations to themselves and they swop ideas and they swop strategies and they keep in touch" (Professional 4: 754). Parents also appeared to receive comfort in listening to other people's experiences of ADHD. For example, "I've been on the [ADHD parenting group] course and that was very good and I did enjoy that 'cos it was meeting other people as well and what they'd experienced" (Parent 2: 506). CYP1 expressed a desire for others to share his understanding of his problems "I cannot help what I do because it is just the way I was born, the only reason I am writing this is because I want you people to know" (L330). Creating a *shared understanding* through a narrative of 'what the problem is' appeared to produce a common language within families and professionals which seemed to give them a feeling of being understood. Consequently, this appeared to contribute to their *acceptance* of the possibility of 'ADHD'.

Acceptance

Creating a *shared understanding* of children's behaviours required those interviewed to *accept* the possibility of ADHD in accounting for the perceived problems. The professionals all described moving to a position of accepting ADHD and rejected opposing views. For example, "I mean the truth is that I feel quite confident I don't feel in anyway swayed by any of their arguments I feel confident in my belief about ADHD erm if you really read some of the things that are reported against ADHD they are inaccurate" (Professional 1: 170). They all described how they felt it could be detrimental to children if ADHD as a diagnosis was not 'accepted'.

The young people also struggled to *accept* the diagnosis, however did not find a more helpful way of understanding the perceived problem. For example, "it would

make myself feel better that I can erm if I didn't have it that I would be able to control myself much easier" (CYP 2: 448). However, accepting the understanding of ADHD as a medical disorder was helpful, "yeah it tells me why I can't do it" (CYP 2: 423). Parents all reported an initial distress at being told their child's behaviour was problematic but appeared to go through a transition of *acceptance* once they had engaged with the possibility of a medical problem "my mind changed 'cos I've got a child with it" (Parent 2: 183).

Accessing support

Knowledge and understanding appeared to create a framework from which to understand and address difficulties and gave individuals new hope and confidence to *access support*. For professionals, this framework is outlined in clinical guidelines, "it is really helpful to have NICE guidelines because it gives you some sort of system to work through" (Professional 1: 606). By becoming part of a *shared understanding* of what ADHD 'is', parents and professionals become streamlined in the information they receive, selecting the information which best fits with their current position. This appeared to be maintained through the presence of written and published literature as well as spoken word.

Once the possibility of 'ADHD' had been *accepted* those involved appeared to engage with the description of having a clear pathway in managing the problem. For example, one professional explained how, if it is felt that 'ADHD' could explain the problem, an appointment is arranged with a Psychiatrist. Once a Psychiatrist is involved it described how "we discuss everything that we have found really and er make a decision, if the parent then decides that they want help and you trial some

medication that's usually the time that that's done" (Professional 2: 194). Diagnosis also gives access to specialist ADHD groups. For example, "as soon as a diagnosis has been confirmed then [service] get involved and they give loads of support and interventions for families in managing ADHD" (Professional 1: 280). Without a diagnosis and agreed *understanding*, parents and children remained in the 'assessment stage' and felt unable to *access support* or helpful interventions.

Parents described more helpful and *accessible support* once they had *accepted* the possibility of their child's disorder. Whilst some of this was attributed to the allocation of resources, such as requiring an educational statement, being referred to an 'ADHD' support group or receiving medication following diagnosis, there also appeared to be a shift in families perception of helpful interventions once 'ADHD' had been accepted.

It appeared that before parents had access to specialist groups they had not benefitted from behaviour management advice. For example,

> "they could certificate the kitchen walls, they wouldn't have to wall paper, because they keep going to these courses, because either they are sent there or they have chosen to be there or if they want to access help or access the facilities, first of all you have to go on parenting course…that is what they are often told anyway.." (Professional 3: 522).

Deconstructing '*Knowledge and understanding*'

The term '*knowledge and understanding*' appeared to be predominantly constructed through professional's perceptions of what constituted the truth about a child's

behaviour. This appeared to relate to societal discourses of ‘cause’ and ‘effect’ within a scientific narrative. Therefore, a medical construct of children’s behaviour appeared to be adopted as the dominant discourse. This involved a way of making sense of the behaviour within a scientific narrative rather than deriving from within the social world. Furthermore, professional discourses appeared to be pedagogically adopted within parents and young people’s constructs of the behaviour, referred to as ‘*shared understanding*’. Those who had positioned themselves within the ‘*battlegrounds*’ of ADHD appeared to then construct an understanding of the behaviour which utilised medical discourses. Within the construct of ‘*knowledge and understanding*’ those interviewed appeared to be creating knowledge and ascribing meaning which held implicit the notion of ‘ADHD’. This implicit understanding appeared to provide joint ownership of the construction of ‘ADHD’ both within parents ‘*shared understanding*’ with one another and within young people’s appropriation of the construct. Therefore, discourses that originated in professional descriptions of understanding the problem became adopted and shared within wider discourses. It could be suggested that such appropriation was adopted through ‘*witnessing transformations*’ in which the story telling of changes in the constructed *battlegrounds* were embraced within parents and young people’s discourses. This sharing and comparison of the dominant discourses could be seen to be empathically engaged by parents and young people in that they re-experienced these ‘transformations’ from a personal perspective. This appeared to link ‘*shared understandings*’ and strengthen discourses of ‘ADHD’ as a medical construct.

Discourses around shared experiences appeared to serve an important function in communicating experiences to others and could be seen to hold a symbolic meaning

for those who experienced the '*battlegrounds*.' Thus, '*knowledge and understanding*' could be seen as an abstract term to communicate the implicit meaning of 'ADHD'. Furthermore, this could be seen to relate to discourses of social comparison, and socially shared emotions, discussed within the construct of *personal conflicts*. This appeared to offer parents and young people the opportunity for the construction of an '*acceptance*' of a diagnosis of ADHD. For example, discourses of 'truth' and 'having knowledge' could be interpreted as self-disclosure which led parents and young people to position the child's behaviour and the resulting '*battlegrounds*' as within the construct of 'ADHD'. Such meaning could also be seen to reflect cultural discourses of 'knowledge and power.' Furthermore, discourses of '*accessing support*' appeared to serve an important function in maintaining the adopted construct through references to the health care system and its role in correcting 'abnormality'. The construction of the need for 'acceptance' seemed to be adopted when attempts to resist the dominant discourses, through searching for alternative understandings, had become futile. This could be related to cultural discourses of 'health and wellbeing,' which appear to be held with esteem.

5.1.3 Investing in ADHD

The term '*investing in ADHD'* is used to describe the position of placing personal and professional resources in the notion of ADHD. An investment in ADHD allows professionals to engage in a process of transforming the situation by diagnosing and therefore treating children and young people. For example, one professional described how she has become active in diagnosing ADHD as part of her professional practice:

> "I think I'm getting slightly more, I don't know how to describe it, less precious about the way I diagnose it so I used to only, I think only really diagnose if I could absolutely exclude other things" (Professional 1: 46).

In adopting this position professionals appeared to be commissioning a framework from which to view the problems they encounter in practice. For example, "I find it quite a rewarding bit of the job because I think if you get the right diagnosis and you know, do a thorough enough assessment and start medication for the right people, then you get a really good response" (Professional 1: 9). They described a process of gaining experience that led to a confidence and belief in their *knowledge and understanding* and thus allows them to advocate this position.

Previously futile attempts to invest energy in coping with the difficulties had left families tired, worn out and feeling judged. Parents were given information which signposted them to re-invest their energy and resources in *seeking a diagnosis* of 'ADHD'. For example, "we give parents a lot of information about ADHD and the behaviours, so that they can recognise that these are the things that come with the mental disorder and you have to work with them and not fight them" (Professional 3: 479). In addition, hope is instilled, for example, "I keep being told that she should start making relationships" (Parent 3: 153). Therefore, both parents and professionals made a decision to *invest in ADHD.*

When faced with presentations, which do not respond to 'usual treatments' an alternative understanding was established. For example, "so it's hard to know whether these children did have ADHD or not in the first place you know maybe it was just a really severe conduct disorder and there are on-going maybe difficulties

within parenting style" (Professional 1: 459). This allowed them to continue to *invest in the notion of ADHD* when faced with information that may have challenged it. Whilst some accounts did express some uncertainty, regarding the '*simple truth*' of ADHD, none of those interviewed relinquished their investment in it.

At times, an investment in ADHD is described as existing in wider social systems, such as education. However, there is a sense of this being abused either for monetary gain or to excuse a child's behaviour. For example, "a child with ADHD erm can, is entitled to some benefits and for support, erm and that's all well and good if it's used for that, erm but in some instances it won't be because that's the nature of people isn't it" (Professional 2: 224). In addition, "I don't think ADHD should be an excuse for every single thing the child does" (Professional 1: 356). These voices appeared to contribute to some uncertainty of the diagnosis of ADHD and its potential for abuse. However, no *investment* in alternative understanding had been made by those involved in this study.

Initially parents described unease with the *decision to medicate* children. For example, "well I don't want to put medication into my child" (Parent 1: 467). However, a sense of *helplessness* and the desire to overcome difficulties led those involved to invest in an approach, which had previously been deemed unacceptable. For example, "so I thought if I didn't put him on that medication I'm not giving him the best opportunities" (Parent 1: 495). By investing resources in the 'brain-blame' position, the possible damage of 'getting it wrong' appeared to be outweighed by the altruistic view of 'curing an ill child'.

Despite reaching a position of *investing in ADHD*, parents and professionals did continue to describe struggles with the management of the situation. For example, "there isn't an easy answer, you know when she's on medication it is easier but it's still things like socialising" (Parent 3: 127). Throughout most of the accounts a position of *actively managing* is achieved or worked towards. This position requires the individual to relinquish the search for a 'cure', which in turn allows them to reinvest energies and to regain a sense of *control*. This could also be seen to serve the function of maintaining vested interests in ADHD and investing resources.

Simple Truth

The construction of the '*simple truth*' about ADHD was interpreted throughout the interviews. This was the identification of there being one clear and honest truth about ADHD, which simplistically explains its existence as within the brain. For example, "that is the way I was born" (CYP 1: 459) and "I've kinda been told that it's a mechanism in the brain that doesn't work properly, its overactive and the only way of making it slow down is by giving it medication" (Parent 3: 20). Accepting this understanding of the problem appeared to alleviate blame from the parent and child. Instead, they were seen to require help to manage. The repeated emphasis on the '*simple truth*' seemed to contribute to maintaining the investment of energy and resources in ADHD and to serve to alleviate any uncertainty in the dominant view of 'ADHD' as a medical disorder. This position appears to offer those involved a concrete definition of the perceived problem, which originates in a medical model of understanding. In addition, it appeared to legitimise the difficulties of the '*battlegrounds*' within the context of the conflicts present between '*social expectations'* and '*personal conflicts'*.

Process of diagnosis

The process of diagnosis appears to be based upon the constructed view of the *simple truth*. It encompasses the process of gathering new *knowledge and understanding*. This involved communicating with parents and schools in the search for information deemed consistent with their existing concept of 'what ADHD is'. For example, "we'd be looking at and assessing in terms whether it fit the criteria for ADHD really (Professional 2: 79). In addition, "the assessment we do is really thorough, really helpful erm, its across school, its across home, you know every aspect of the young people's life" (Professional 2: 113).

At times health care professionals described an uncertainty about diagnosing a specific child. However, previous experiences alleviated this, in which they believed that making a diagnosis would bring about the desired change for the family. For example,

> "if there were, you know, really bad attachment problems or really severe conduct problems it might make me not think of ADHD so some of these children I might not have treated but I think now and I think I'm not alone in this from talking to colleagues that are similar that if they tick all the boxes for ADHD even if attachment is still a major part of it actually medication can still really help" (Professional 1: 50).

Professionals often engage with families when they have been stuck in the *battlegrounds* of trying to manage alone. Attempts to offer behaviour management advice at this stage appear futile. For example, "I mean it's not that I don't try other treatments I still will sort of you know throughout the assessment process use other

treatments" (Professional 1: 88). However, with experience she found value in prescribing medication earlier, which required a diagnosis.

In the absence of an established 'test' for ADHD and the perceived potential for 'misuse' of the diagnosis professional's described the use of subjective assessments of the child's 'fit' with social systems. This seemed to contribute further to a perceived need for the involvement of the healthcare system. For example, Professional 1 describes how she assesses a child's level of impairment based on social and family functioning:

> "I mean it's hard I don't use any sort of formal testing but its more just sort of descriptive things that I would get after seeing a patient and their family so often, if there's you know a parent at the end of their tether and there's significant you know arguments all weekend and if at school the teachers say well actually their concentration is impacting upon their ability to actually access the syllabus and the kid's say no one wants to play with me I make a subjective judgement about the level of impairment" (Professional 1: 242).

Once parents had invested in the notion of ADHD they reported a sense of battling to receive a diagnosis, in which they were referred to various different services before finally arriving in front of a psychiatrist. One parent described the emotional impact of being told conflicting information about her child's diagnosis from services.

Deciding to medicate

In all of the accounts, the requirement to medicate was introduced shortly following or alongside a diagnosis. For example:

> "Erm I think I think we had, after the diagnosis and deciding to put her on mediation we had 3 weeks and the only way round it was as I say I started making phone calls and researching on the internet and spoke to this mum and spoke to the lad and then me mum kind of heard of somebody who had a little boy and he'd just gone on medication so she phoned me up and I had about an hour and half with her, so it was trying to make sure that we were doing the right thing, that was the thing and we spoke to the school and discussed it with school because obviously school needed to be on board cos they give [child's name] her medication as well and they were fully supportive" (Parent 3: 221).

Parents reported a new internal conflict when faced with the decision to medicate. They described an initial incongruence with the idea of medicating their child against a desire to help their child 'fit in'. A process of searching for *knowledge and understanding* appeared to be once again engaged with in order to resolve this conflict. The parents appeared to reject information that went against their investment in ADHD and were left with limited choices about how best to manage the difficulties. None of the parents interviewed identified alternative options for treatment. For example, "No nothing, no nothing, we asked was there anything else, but we wasn't offered anything else" (Parent 3: 263). At this time, parents described continuing to be in the mist of the *battlegrounds* of trying to gain *control* of activity,

but feeling *helpless*, partly due to the hard work required. The decision to medicate appeared to be an empowering one filled with hope of *transformations*. Once commenced on medication young people and their parents described an immediate improvement in behaviour. The *transformations* witnessed appeared to lead those involved to conclude that ADHD adequately described the perceived problems. For children and parents it gave them a framework for understanding the difficulties "my tablet adds something to my brain so that I can concentrate" (CYP 2: 428). This reinforced their belief in the *simple truth*. The parent's emotional discomfort of giving a child medication appeared to be supressed. Whilst one child reported a dislike for the medication, another reported a perceived need to continue medication in order to achieve in education. A position that appeared to have been adopted with age.

Professionals appeared to have already *invested* in medication's ability to *transform* situations. They had a wealth of experiences in which medication had helped transform lives and had a secondary effect on a child's functioning, social relationships and the ability to access education. Such accounts of the benefits of medicating appeared to outweigh any contradicting or unknown information, such as long term effects, reported side effects and possible dangers of medicating young people.

Active management

In all the accounts, the need to increase medication and the idea of medication 'wearing off' was introduced. Parents and schools began to once again report an increase in difficulties and their investment in the 'cure' was relinquished. This

process required parents and professionals to re-explore ways of managing the described difficulties. A process of behaviour management and changes within the child's environment ensued. For example, "it's not a cure is it you know at the end of the day the medication is not a cure it's just to help" (Parent 1: 593). A new narrative was developed which highlighted medication as an opportunity to reduce tensions and relieve struggles. In many cases, this involved engaging with third sector services that were seen to become actively involved in supporting families in a meaningful way. For example, "I'd maybe refer them to a parenting group erm get [service] involved who are a really helpful organisation who who work with parents in the home looking at strategies for managing difficult times like meal times and bedtimes" (Professional 1: 260). Despite medication families returned to the *battleground* of struggling to manage. For example, "I don't we don't cope that is what I am saying we don't cope with it… we started a while ago with chart" (Parent 3: 948). Within this extract, the parent has found the medication less effective than first thought for her child and she is now struggling to implement behaviour management strategies.

Deconstructing '*investing in ADHD*'

It is interesting to note that '*investing in ADHD*' also appeared to be expressed through dominant discourses that create ADHD as a medical construct. Central to this notion was the reliance on medicalised language to construct the '*simple truth*' of ADHD. The idea of 'cause' and 'effect' within scientific narratives, especially in relation to medication, was engaged which constructed the notion of ADHD as existing within the brain. When discussing their child's behaviour parents drew upon biological accounts of the problem. References to the 'transforming' effects of

psychoactive medications were also frequently utilised to bring meaning to the '*simple truth*'. This seems to draw upon the heuristic nature of science to construct an understanding of the complexities of the difficulties present in the '*battlegrounds*'.

The foundations of the construction of ADHD as a medical diagnosis appeared to be formed within professional's voices. Thus, parents and professionals who jointly constructed this understanding as 'truth' also adopted the repeated storytelling of ADHD as existing within the brain. This positioning appeared to hold an important role in serving to maintain the medicalised construct of ADHD in which explorations of more interpersonal constructions were foreclosed. The interpreted medicalisation of children's behaviour appeared to be strengthened by references to diagnostic criteria and *'the process of diagnosis'*. In addition, the existence of psychoactive medications and their '*witnessed transformations*' appeared to cultivate a discourse of the success of medication and the heuristic value of the '*simple truth*'. These discourses held implicit meaning in the '*decision to medicate'*. This provides further strength to the notion of '*investing in ADHD*' that could be seen to alleviate the negative emotions which were voiced within alternative locations for the responsibility for 'ADHD'. Thus, any alternative positioning of ADHD was perceived as inviting blame upon the child and/ or parent. In addition, discourses in relation to the potential for harm in medicating children, possibly stemming from cultural discourses of 'childhood', appeared to serve to internalise the view of the dominant medical construct of ADHD.

5.1.4 Social Expectations

Societal and cultural discourses mediate social norms. The term '*social expectations*' relates to the perceived expectations on children's behaviour and the major social factors which impact upon experiences of the diagnosis and management of ADHD. These were *education, social success, childhood development* and *the role of the professional*. Concerns over a child's behaviour arise when they are considered to have deviated from the accepted norm. For example, "the ADHD child who is, his behaviours are not socially acceptable, ok you can have bad days, you can have bad months, but these children are bad every hour if that is the right word" (Professional 3: 556).

The importance of Education

Schools are consistently cited as being the first to report difficulties in managing a child's behaviour, referred to as "raising the red flag." The expectation is that children "sit down at certain times and they've got to do this and they've got to do that" (Parent 1: 327). Prior to the child attending school any 'problematic' behaviour was perceived as manageable, "we thought it was him and it would settle down" (Parent 2: 85) and "he went to pre-school and they managed it" (Parent 2: 198). The perceived level of impairment on a child's functioning is a large factor in initiating concerns about a child. Children's behaviour is seen to disrupt the whole classroom and "impairs the learning of the rest of the class" (Professional 3: 49). Schools are described as lacking the resources to cope with the occurrence of children who do not conform to the rules and expectations of the education system. For example, "Schools are not helpful for young people who are impulsive who need to walk around a bit and sort of be freer" (Professional 2: 676). Consequently, schools are seen as requiring flexibility in their expectations of the child. However, due to the

inflexible nature of such a large social institution, problems appeared to become redirected towards parents and dispersed into the health service.

The way these problems are brought to the attention of parents can have a huge impact on the resulting course of action taken. One parent described how "he moved to year one and I got called in by his teacher" and "every time I spoke to her I used to go home crying" (Parent 1: 255). Whilst one professional stated, "the majority of the teachers are very desperate for the diagnosis because it helps them in managing the whole classroom" (Professional 1: 153).

This involved seeking help from within the health care system and led to the creation of a *shared understanding* between health and education services. Schools were also cited as an important part if the assessment process and therefore heavily influenced decisions to diagnose. Furthermore, a *shared understanding* of ADHD was seen to be compromised if schools did not '*invest in ADHD'*. For example, those that did invest were seen to facilitate the management of a child's problems, "ADHD friendly schools which means that the management or the policies are such that there is flexibility" (Professional 3: 44). The importance of education was seen to influence families' decisions to *invest i*n ADHD. For example, "there isn't another avenue, because she needs to get on in school and she needs to learn, and I don't see another way of getting her to learn, we've tried for years teaching her things, you can't even get her to sit down long enough to teach her" (Parent 3: 1120). This perhaps illustrates the cultural importance of academic performance.

Social success

Parents' desire to facilitate their child's success appears to stem from societal discourses of parenting. This success is measured on the child's ability to conform to social norms, 'fit in', and ultimately flourish. Termed '*social success'* those interviewed in the study consistently identified the importance of education, learning, and the existence of meaningful social relationships as contributing to a person's perception of a child or the child's own self-concept. For example, "I just want him to be the same as everybody else erm I think that is, sometimes is what is hard work with him, is that people just look at him and think he's like ordinary but he's not " (Parent 1: 1198). Once children have been identified as having difficulties, the desire for them to be accepted appears to limit understandings of their difficulties. One parent compares her view of diagnosing and medicating her child to the medical problem of asthma, stating, "you would give them their inhaler so why not give them this to help them calm down and to fit in with the rest of society" (Parent 1: 1230). This illustrates an *acceptance* of the '*simple truth*' in an attempt to facilitate a child's social success. Professionals also described the perceived need to medicate in order for children to 'fit in'. For example, "you see children who used to have no friends now invited to parties and going round to friends for tea" (Professional 1: 420).

There appeared to be concern with the negative consequences of reduced *social success*. When faced with the possibility of her child being 'different' one parent described "you'll see on their faces, as like, not unsure, like weirdo, that upsets me as well" (Parent 2: 678). Another described "yes he is the only one and she made me feel that big [hand gesture to show a small gap between thumb and forefinger]"

(Parent 1: 280). This was also voiced by young people, one of which expressed feeling" quite alone actually" (CYP1: 160).

Developmental Norms

Throughout the interviews, the desire to conform to societal expectations of a child's development is a recurring theme, which appeared to residually place expectations on children's behaviour. Those considered to have 'ADHD' are often described as immature or below the developmental stage of choosing a more acceptable set of behaviours. For example, "I think as he gets older again I think he'll then realise, well actually I don't think I should be behaving like that, I think he'll always be an immature boy but then lots of boys are immature anyway aren't they but yeah I think he will always be immature." (Parent 1: 1108). References to children 'growing out of it' are made throughout the interviews, thus voicing hope that the 'normal' developmental pathway will be resumed.

In parallel, it is frequently suggested that such measures of development are unrealistic and that social discourses of childhood are placing ever increasing demands on children. An emotional struggle between the desire to avoid exclusion from social systems and the belief that social expectations of children's development are too restrictive is evident throughout the data. For example, "it is a bit silly what you're doing but then like [my husband] said years ago he was playing with his action men at 10 because years ago you didn't have all these computer things" (Parent 1: 1158).

The role of the professional

Throughout the interviews, there exists a hope that children's identified differences will be resolved and risks of social exclusion and isolation will be minimised or reversed. Schools require children to be 'statemented' in order to respond to their behaviour and health services are thus involved to account for the perceived differences. For example, "before they get diagnosed the reason they've been taken to the GP is actually they are failing, they are failing at things within the home, they are normally really struggling in school and struggling with friendships" (Professional 1: 552). There appears to be an expectation amongst parents that health professionals can explain and 'cure' the problems that are causing the identified difficulties.

Awareness of the controversies regarding the existence of ADHD were identified throughout parent and professionals accounts. For example, "I come across lots of professionals and families that don't agree with it" (Professional 1: 107). These controversies appeared to undermine the role of the professional, which was overcome by emphasising successful outcomes in their practice and reinforcing the role of the professional as 'helper'. For example, "as I got more experienced and you know and hopefully making more accurate diagnosis over the past years I generally find that you know that nearly all of my patients are doing really well" (professional 1: 16).

Deconstructing '*Social expectations*'

It is interesting to note that the term 'social expectations' came predominately from parent's voices of what they perceived to be the pressures within society. Discourses

of '*social expectations'* appeared to be constructed through references to the '*importance of education*,' '*developmental norms*' and '*social success*.' Thus, parents constructed a perceived reality of the pressures within their lives stemming from within social systems. Discourses in relation to attainment and education produced a framing of the importance of education in society and a child's place within this. This discourse further links to the medicalisation of childhood in that medical language is used to frame children's behaviour in the classroom. It seems that when a child's behaviour was interpreted as impacting upon educational attainment constructs of the medical model of 'abnormal' behaviour were utilised. Therefore, constructs of academic achievement and behavioural conformity form an ideological rationale that fuels parents' and professionals' concerns over the '*battlegrounds*'. Discourses of '*social success'* and '*developmental norms*' can be interpreted as providing further ideological rationale for the adopted position of parents. These can be seen in relation to discourses of childhood in which parents appeared to draw upon cultural constructions of childhood development that produce culturally relevant expectations for the appropriate behaviours and activities of children. This could be further related to parent's perceptions of their child, drawing upon constructs of 'normal' and 'abnormal' behaviour. These narratives around childhood development construct a cultural expectation for the role of the child in which those whose behaviour falls within that deemed unacceptable in the 'a *battlegrounds*' appeared to become perceived as the 'child with ADHD'. This seemed to allow parents and professionals to maintain the construction of childhood as valued within society.

Alongside discourses of childhood, it appeared that cultural discourses of '*the role of the professional*' were also utilised in the construction of ADHD. The '*role of the*

professional' appeared to hold implicit meaning in the story of ADHD. The entrenched nature of medical discourses and the power of 'the professional' appeared to further emphasise the construct of ADHD within a medical model. Thus, the positioning of ADHD could be interpreted within discourses that position the professional as a gatekeeper of 'knowledge'. In turn, the importance of 'knowledge and understanding' is integral to stories of ADHD and therefore, it could be interpreted that '*the role of the professional'* further articulates a story of ADHD, which originates within a medical construct.

5.1.5 Personal conflicts

When a child's behaviour is deemed unacceptable, a search for the *causes* of the behaviour was commenced which involved attributing *blame*. For example, "I guess a child that's coming with difficulties in school or at home, that behaviour is coming from somewhere, so it's about identifying where it could be sometimes it can be that the child has ADHD and that's caused the social difficulties and parents separating or whatever so it's about looking at it from both, from every angle really" (Professional 2: 499).

This search is accompanied by *emotional struggles* in which those affected appeared to struggle to make sense of, the highlighted difficulties. For example, "he's such hard work, such hard work but he's a gorgeous boy" (Parent 1: 21). The desire to *avoid harm* was perceived as contributing to the conflict experienced by parents and professionals as they attempted to balance the pressures of *societal expectations* and a desire to protect children and facilitate their success. Perceptions of others and issues with social identity and damage to the *self-concept* appeared to further

contribute to these conflicts. For example, “you are being really silly and so we do constantly say that to him erm and maybe that doesn’t help you know maybe that doesn’t help his confidence I mean we’ve discussed it we’ve sat down me and [husband’s name] and discussed and we’ve said we maybe shouldn’t say those things to him but when he is on top form and he’s behaving like that it’s hard” (Parent 1, 792).

Blame/causation

Once problems have been reported parents described a sense of blame. Terms such as ‘behaviour difficulties’ appeared to be perceived by parents to suggest that they are to blame, perhaps due to inadequacies in parenting practices. For example, “yeah a lot of people think that it’s behavioural and they’ll look at you, y’know, they say get hold of that child and you just want to strangle them” (Parent 2: 19). Parents search for possible reasons to account for the behaviours, such as, genetic contributions, food additives or a possible disorder. At times, the difficulties are located within the child, such as ‘naughtiness’ or defiance. By *investing* in the existence of ADHD, this blame appeared to be alleviated and the ‘brain-blame’ position was adopted. For example, “because I know myself that it’s not me, it’s not him being naughty, he has got [ADHD]” (Parent 2: 179). The positioning of blame appeared important in the context of *social expectations* and *personal conflicts*, which appeared to mediate a sense of responsibility for the perceived problems.

Emotional struggle

Parents described a variety of feelings such as distress and disbelief at the possibility of their child being ‘different’ from others. One parent described how “you know I

was distraught" (Parent 1: 270) when school voiced concerns to her about her child's behaviour. Within the interviews, parents also identified feelings of shame and guilt that were alleviated once a diagnosis of ADHD was received. For example, " I do get upset about it and annoyed as well, I feel like going around with a big sticker he has y'know a condition it's not naughtiness" (Parent 2: 38). All the parents interviewed described constant worries about the future. For example, "you're worrying to death, so also 'cos she doesn't eat when she's on the medication, you are worrying about getting food into her" (Parent 3: 436). Other areas of worry were factors regarding education, social relationships, their child's happiness, and perceptions of others. Parents voiced uncertainty that they are 'doing right' by their children in the face of so many different opinions. There also appeared to be a sense of ambivalence between the *acceptance* of a diagnosis and a desire to *accept* the child 'the way they are' or that they may 'grow out of it'. Therefore, creating a battle between what individual's feel to be 'acceptable' and a sense of being judged by others. Such voices appeared to stem from the existence of competing discourses of the perceived problem.

The young people interviewed revealed emotional struggles at being viewed as 'different' and finding it hard to '*control*' themselves. The main feelings they expressed were anger and frustration in relation to their difficulties. For example, "when my mum and dad say you've got ADHD and you can't help it it gets me angry and I just, leave me alone and I get really frustrated I can't help me anger" (CYP 1: 97).

Avoiding harm

Professionals described a desire to *avoid harm* and 'reverse awful' situations. This was achieved through investing in the '*simple truth*', which located the difficulties within a medical framework. However, at times an underlying sense of uncertainty was voiced. For example, one professional described "we spend lots and lots of money on medication for young people, is it right that we should do that, that's always something in the back of your mind you know in sort of twenty years are these young people gonna have some side effects" (Professional 2: 749). The possibility of 'causing harm' was perceived as contrasting with professional's sense of satisfaction at helping families and their '*role as professional*'. However, an awareness of a more 'complex' understanding of children's behaviour, in which social difficulties and the child's context is important, was also identified. For example, "I think that then becomes a difficulty if they were looking at a diagnosis because it's not a true diagnosis it's how they're presenting but it's not because of ADHD difficulties it's because of social difficulties whatever that may be" (Professional 2: 269). This appeared to cause a conflict within professionals who portrayed 'complex' understandings of the difficulties to offer less potential to 'help.' Therefore, in a perceived attempt to preserve the current understanding of ADHD an alternative explanation is sought for 'complex' families, such as "conduct disorders" (Professional 1: 536).

Parents engaged in a discourse of their child requiring help which further fuelled the search for a 'cure' in order to avoid social exclusion for their child. For example, "I was just thinking that they would come up with something and yeah this is how we deal with it, this is how we help them, that's what I was focused on, so to go in there and to say right here's the prescription for Ritalin and its… I was like that.. you

know… it's just not, you don't want your children on medication do you?" (Parent 3: 204). In this example, the parent had not foreseen that medication would be the 'answer' but with limited choices of ways to reduce the perceived difficulties, medication became her only option. The desire to balance the positive and negative perceptions of children is often helped when the child receives medication, thus avoiding the potential for harm. For example, "they sit in appointments and listen to all these dreadful things about them, erm so I think parents can use medication as an opportunity to be able to really praise their kids and give them jobs to do that they can do well" (Professional 1: 557).

Self- concept

Throughout the interviews, children identified negative self-beliefs and described themselves as inadequate or different. For example, "I'd rather be a normal person rather than someone who has got a medical disorder" (CYP2: 488). In addition, "I just don't want them to know about me that's all because if I knew about somebody else I wouldn't laugh and they would laugh at me" (CYP 1: 342). They also appeared to struggle with the desire to be seen in a positive light and a sense of shame at the possibility of not being 'as good' as others. This can be illustrated through CYP1's description of his drawing skills "I'm not that good I'm not the bestest drawer in the whole entire town… you don't have a bestest drawer do you? Everybody's good at drawing. Some people may be not be can't even draw, Yeah I'm quite good at drawing, Now I've said that I'm probably not." (CYP 1: 215).

Parents began to see themselves as different to 'normal parents' and feel that others also judge them as inadequate or different. For example, "because I don't think there

is a lot of support for parents like us" (Parent 3: 1030). This has a residual impact on how they perceive their children and their behaviour. For example, "we can't just go along the way that you'd bring up a normal, it sounds awful that, a normal child" (Parent 2: 906).

The professionals interviewed highlighted the importance of their professional identity in creating job satisfaction. At times the presence of alternative views about ADHD, controversies over medication and possible denials of the existence of ADHD appeared to lead to a sense of uncertainty and a need to defend their position in order to preserve their identity as the 'professional' and resolve the emotional struggle. This is illustrated though one professional's description of job satisfaction being enhanced through diagnosing and treating families with ADHD. For example, "nearly all of my patients are doing well so I have gone from really not liking it and it being a real awful part of the job to actually you know choosing to do it more and more" (Professional 1: 16).

Deconstructing '*personal conflicts*'

The concept of '*personal conflicts*' appeared to stem predominantly from parental discourses concerned with morality, and the cultural representations of the parent. Here discourses of '*blame*' and '*causation*' were seen to further construct the medicalisation of children's behaviour. The notion that children may be responsible for the perceived behaviours can be seen to contrast with the rhetorical investment in the notion of children as free from blame. This was interpreted, within the discourse of children as 'moral' and 'innocent'. Furthermore, discourses which engaged in the potential responsibility of parents in 'causing' the perceived behaviour can be seen in

contrast with the rhetorical investment in ideological views of the parent as nurturer. Therefore, the positioning of ADHD within the brain appears to strengthen the medicalised construct of ADHD and may serve to relieve the potential challenges that present in alternative constructs. This appeared to be as a result of competing discourses within medical and cultural constructs of 'ADHD'.

The perception of self (*self -concept*) appeared to be constructed through discourses of 'normal' and 'abnormal' behaviour. In which, narratives around expectations for children's behaviour served to influence young people's sense of self. Whilst young people's narratives of negative self-concepts appeared to be strong these perceptions seemed to be appropriated through adult narratives of the child's behaviour. Thus, rhetorical descriptions of the child within medical discourses appeared to overlap with young people's developing sense of self. Such descriptions can be interpreted as intrinsically linked to concepts of '*social expectations*' and discourses of childhood. The existence of narratives around children's negative *self-concept* appeared to conflict with discourses of the *'nurturing parent'*. This was articulated in terms of '*avoiding harm*' through the medicalised construct of ADHD. Therefore, discourses relating to '*avoiding harm'* appeared to serve to maintain the medicalisation of ADHD and also the '*role of the professional*.'

Throughout parental narratives there appeared to be a high level of rhetorical work around the communication of emotion. This appeared to contribute to the construction of 'parental pressures' which seemed to further emphasise the importance of the difficulties within the '*battlegrounds*' and the importance of '*knowledge and understanding*.' Thus, '*emotional struggles*' could be seen as symbolic of the interpersonal benefits of '*investing in ADHD*' and particularly the

construction of the '*simple truth*' which could further contribute to a '*shared understanding*.' Furthermore, the notion of '*social expectations*' as framing discourses around societal constructs of attainment and development, could be seen to contribute to narratives around emotional expression. In which, parents perceived their level of '*emotional struggle'* to be beyond that deemed appropriate within 'normal parenting'. This was articulated through parents' investment in discourses around the '*hard work*' within the '*battlegrounds,*' which subsequently became framed within a medical construct itself. For example, references of parents requiring psychoactive medication to cope. Therefore, whilst the expression of the struggles within the '*battleground*' served to contribute to the construction of ADHD as a medical construct, this also appeared to be mediated through social discourses, which construct the boundaries of emotional expression and expectations for children's behaviour. Furthermore, the construction of ADHD can be interpreted through the strong discourses that stem from medical language and practice that is situated within the medical model, including diagnostic criteria, medicating and *accessing support* from medical professionals. Thus, the practice of '*investing in ADHD*' appears to occur within the construction of the medicalisation of ADHD and the creation of the '*simple truth*'. This is further influenced by the avoidance of alternative discourses, which appeared to be framed as detrimental.

5.2 Theoretical Model

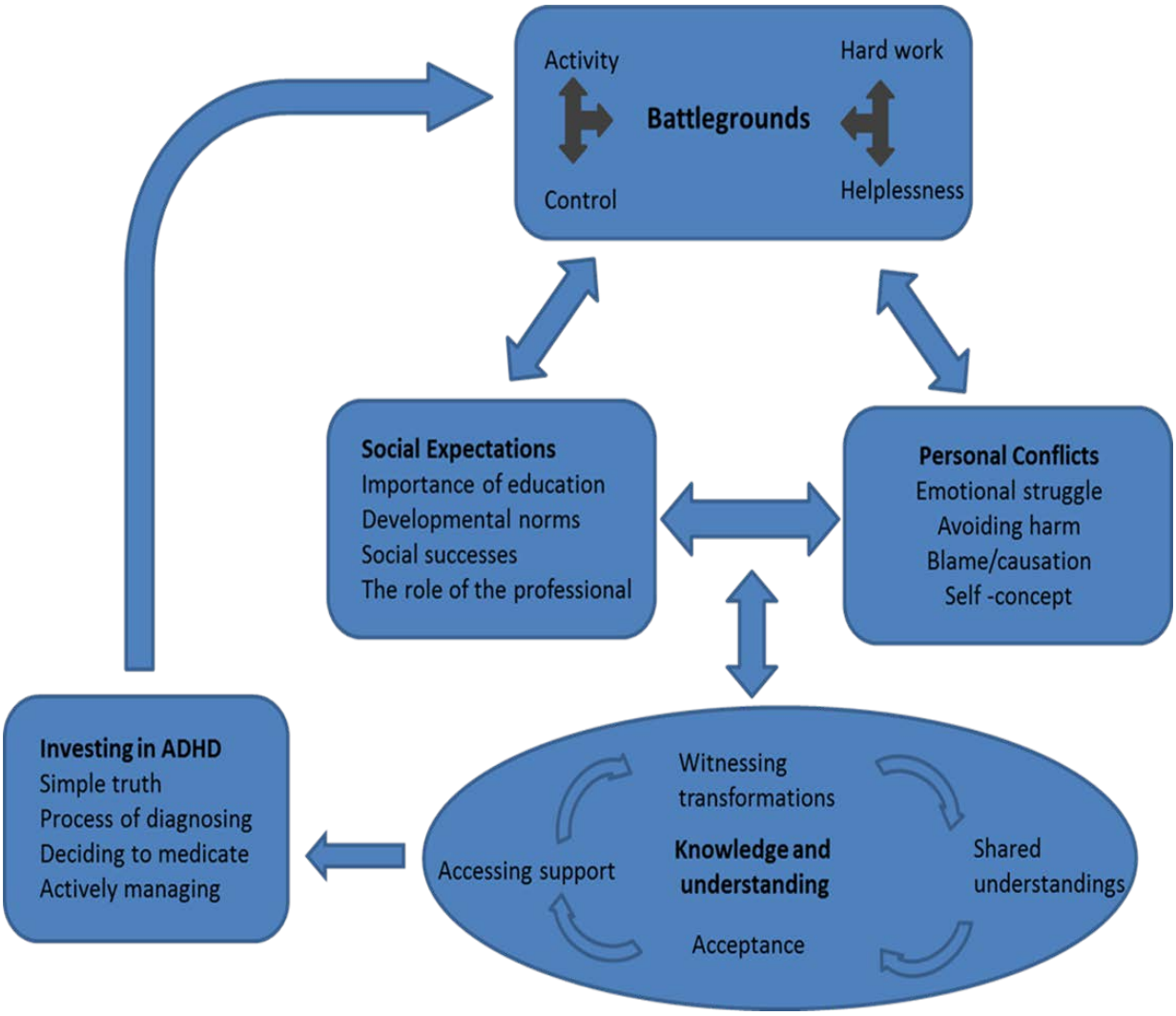

Figure 3. A diagrammatical representation of the categories and subcategories.

5.2.1 Central Storyline

The experiences of those interviewed revealed a process of '*investing in ADHD*'. There was some interpretation of an awareness of opposing views of ADHD and competing discourses, as a medical or cultural construct. This was articulated through descriptions of controversies over its diagnosis and treatment. However, all those interviewed *invested in ADHD* as a medical construct. This involved the belief

of the *simple truth* of ADHD, in which the problem was located within the child's brain. *Investing* conceptualises the personal and professional resources individuals gave to the *simple truth* of ADHD. This conceptualisation of the core phenomenon can be seen as intrinsically related to the subsidiary categories. Essentially the 'problem' conceptualised as the *battlegrounds* was framed within the conflicts present in the categories *social expectations* and *personal conflicts*. In addition, alternative explanations of 'ADHD' were limited due to the presence of these conflicts. The category *knowledge and understanding* could be seen to offer a way to address these conflicts. This served to empower those in the *battlegrounds* in which *investing in ADHD* and the *simple truth* appeared to offer the most satisfactory position for those involved.

Children's excessive *activity* levels and the degree of *hard work* involved were consistently framed as the difficulties of 'ADHD'. Futile attempts to gain *control* of the problem were shown to contribute to the *battlegrounds* of 'ADHD' and left families and professionals in a state of *helplessness*. These perceived problems of 'appropriate' and 'inappropriate' behaviours appeared to be constructed through cultural discourses of 'parenthood' and 'childhood'. Once the problems were reported four main personal conflicts appeared relevant. Initially, the struggle to establish the *cause* of the problem and avoid *blame* was in conflict with the desire to *avoid harm* or limit children's chances of *social and educational success*. The identification of the problem also led to *emotional struggles* that influenced *self-concepts*. These aspects appeared to be primarily constructed through discourses of 'responsibility' and 'emotional expression'. *Personal conflicts* appeared to be inherently linked to *social expectations*. The social desire for children to 'fit in' for

the purpose of *educational* and *social success* was a strong factor in the construction of the difficulties. Cultural discourses of 'normal childhood *development*' and a notion of the *importance of health professionals* to understand and 'cure' problems appeared significant.

A search for *knowledge and understanding* commenced in an attempt to resolve these battles and conflicts. Within this search parents and professionals listened to and recounted stories of *transformations* in children and families with similar problems. This instilled hope for similar outcomes and the potential for a 'cure'. This category appeared to be constructed through discourses of 'knowledge and power' that draws on scientific discourses of 'cause' and 'effect'.

The development of knowledge and understanding appeared to offer those in the *battlegrounds* a way forward, which was again mediated and maintained by *social expectations* and *personal conflicts*. The belief in the '*simple truth*' of ADHD brought a predefined framework for understanding and treating the problem, which originates in medical discourses. Therefore, those involved found meaning in the medical construct of ADHD and chose to '*invest'* in this position.

The trajectory of those involved was not always a linear one and throughout the process of diagnosis, states of conflict continued. Professionals often described the challenges and battles they faced in clinical practice and how these were resolved through a continued *investment in ADHD*. Families again experienced *personal conflicts* and pressures from *social expectations*, which led to disempowerment as they struggled to get their child *diagnosed*. A clear diagnosis restored a sense of *knowledge and understanding*. Shortly following this, families were plunged into a

new dilemma of *deciding whether to medicate* their child. Again, this process went full circle until a sense of '*knowing*' was re-established. In time, families often returned to the '*battlegrounds*' when medication began to 'wear off' and families then commenced a new search for realistic ways of coping. This appeared to be an on-going struggle of *active management*. Therefore, despite *investing* in 'ADHD' and receiving a diagnosis and medication the original *battle* between *social expectations* and *personal conflicts* remained throughout. Therefore, alternative constructs of ADHD were seen to offer less meaning. However, when faced with competing discourses those involved continue to further invest in the notion of the *simple truth* perhaps in an attempt to avoid further tensions between the triad of *battlegrounds, social expectations* and *personal conflicts*.

5.3 Relationship with existing literature

The following sections will now discuss the relationship of the current research with existing literature. This allows an exploration of the emerging theory and its properties within the context of the wider literature.

5.3.1 What is ADHD?

'Battlegrounds' was the term used to encapsulate the core 'problem' of ADHD, which involved the identification of children's behaviour as difficult to manage. This description of the problem at a behavioural level is in keeping with the current diagnostic criteria used in clinical practice. The 'significant inattention, impulsiveness, and over activity' described in the DSM-IV (APA, 2000) was consistent with parents', professionals', and young people's identification of what 'ADHD' is. In addition, the notion of ADHD as a medical disorder heavily

influenced the construction of the problem. In the current study ADHD appeared to be constructed as a difficulty within the child's brain requiring medication. Within the existing literature, debates exist around the notion of ADHD as either a cultural or a medical construct. However, research that takes a positivist approach to the study of ADHD has remained inconclusive as to the exact cause (Durston, 2008; Kieling, et al., 2008). The current study suggests that those interviewed adopted the belief that a cause does exist. This is in contrast to the significant shift in the focus of research towards understanding ADHD as a heterogeneous set of behaviours which could be understood in terms of cognitive, genetic and neurophysiological differences (Chan et al., 2009; Martel, 2009; Snowling, 2009; Sonuga-Barke et al., 2009; Taylor, 2009).

The current study provides insight into how the concept of ADHD is socially constructed through language and discourse. The processes through which people construct meaning of ADHD can be identified as emerging from social representations of childhood and parenthood. The current analysis appears to suggest that theories stemming from medical models of diagnosis and pathology have become widely accepted into discourse around perceived difficulties with behaviour, inattention, and impulsivity. This appears to have been constructed in relation to the concept of 'childhood normality' and the creation of expectations for 'parenthood.' Thus suggesting that perceptions, which are culturally and socially embedded, create knowledge about the appropriateness of children's behaviour and parenting practices. These in turn influence the representation of ADHD. Within current literature ADHD has been represented as a medical disorder. This construct has been utilised to resolve the conflicts of the '*battlegrounds*' identified in the current study. The shift in focus of current literature, discussed previously, which focuses on ADHD as a

heterogeneous set of behaviours, could be seen as less commonly accounting for ADHD due the contentions in blame and responsibility which are identified in past literature and the current study.

5.3.2 The simple truth

The current guidelines clearly state that a diagnosis of ADHD should not imply medical or neurological cause (NICE, 2009). However, throughout the study, awareness of environmental causes of ADHD was minimal and all those interviewed identified ADHD as a medical disorder with neurological causes. This appears to contribute to processes of the social construction of ADHD. In addition, The British Psychological Society, and the Royal College of Psychiatrists jointly published the NICE guidelines. However, within the current study Psychologist's did not feature within the practice of ADHD. Those who take a critical stance towards ADHD practice, have suggested that placing the perceived problem within a medical model, with the role of medical professionals as privileged, creates a dependency upon psychoactive medications as the only 'treatment' and limits understanding of the difficulties (Radcliffe and Newness, 2005). Within the current study, the practice of placing the problem within health services and subsequently medical professionals appears to reinforce the notion of ADHD as a medical disorder and ultimately limits management approaches used in practice. Such practice can also be discussed in relation to the process of socially constructing ADHD. Placing ADHD in the domain of medical professionals could be seen as a result of discourses which serve to reduce socially constructed conflicts between children's expected behaviour and the role of parenting. This could, for example, also be related to personal conflicts, such as, the self-concept which contributes to the construction of ADHD as existing within the

brain. Within the current study, this relates to the development of social identity and the perceived need to avoid contributing to a child's negative self-concept. Therefore, placing control of behaviour within the brain thus alleviates blame and causation as within the child's voluntary control.

The investment in a medical construct appeared to be self-regulated by all parties involved, perhaps due to a lack of meaningful understanding in alternative discourses. In contrast, it could be viewed that access to health care services and medical professionals, helped parents to overcome conflicts and struggles at times when they were under a great deal of pressure and required specialist support. Therefore, it could be considered that individuals may actively choose this path even if alternative ways of managing and understanding were more available. Awareness of alternative ways of understanding of ADHD was present; however, predominantly came from professional accounts than parent and children. There was less emphasis placed on these descriptions and they appeared to hold less meaning for the participants. In addition, there was an explicit awareness that children were being given medication to 'fit in' to social expectations. This may suggest that individual's more actively chose medical explanations of ADHD than those who write from critical perspectives of ADHD may account for (Bolton, 2004; Timimi & Taylor, 2004; Baldwin & Cooper, 2000; Kutchins & Kirk, 1999). Such discussions may relate to research that highlights the role of diagnosis in validating individual's difficulties and legitimising personal struggles (for example, Lafrance, 2007).

The current study can also be related to research which highlight the role of 'mother-blame, brain-blame' debate (Blum, 2007; Singh, 2004). The current emerging theory suggests that both parents and children work towards alleviating their own sense of

responsibility for difficulties. By adopting the 'brain-blame' position, which in this study emerged as the '*simple truth,*' both children and parents were able to move on from the personal conflicts and reduce pressures from societal expectations by placing responsibility, or causation, within a medical framework. This is consistent with the concept of concerted cultivation (Singh, 2004) in which the pressures of social life are seen to impact on self-concept and investment of resources to overcome perceived difficulties.

5.3.3 The role of parenthood

Within existing literature the importance of parent-child relationships in the construction of ADHD are important. The current emerging theory was consistent with aspects of parental schemata in the management of ADHD identified by Bull and Whelan (2006). Of the eight schemata identified in this study, a number are consistent with the emerging theory in the current study. For example, 'Perceiving the child with ADHD as different from others', it was identified that children's behaviour often cited as 'inattentive, demanding, and hyperactive' separated them from other children. In the current study this is identified in the category '*battlegrounds*'. Secondly, 'aspirations for the child with ADHD' described parents' desire for their child to develop into an 'ideal adult' and be happy. This could be compared to the subcategory '*social success*' in the current study. 'Medicating the child with ADHD' and 'managing the child with ADHD' encapsulates the different management approaches attempted by parents to '*gain control*' which were also present in the current analysis. Bull and Whelan (2006) suggest that 'parental authority' was seen as inappropriate in managing children's behaviour, similarly, in the current study parents attempts to '*gain control*' were seen as futile and the need

to *understand* where the behaviour came from replaced the need to control the child. Finally, comparisons can be made between the subcategory '*hard work'* and the struggles reported by mothers within Bull and Whelan's study. Bull and Whelan's study aimed to identify a set of 'schemas' present in parent's views of ADHD. The current study can be seen to suggest that such patterns of thinking and organising knowledge are socially created.

It has been suggested that the role of fathers within research on ADHD requires further attention (Bull & Whelan, 2006; Lifford, Harrold & Thapar, 2007). Interestingly, the current research only recruited mothers despite attention being paid to invite both genders to the study. However, mothers in the study did make some reference to their partners. Within these accounts, fathers were portrayed as sharing struggles, however appeared less likely to adopt medical explanations than mothers were. For example, "he will grow out it". These comments may allude to similar findings present in previous studies, however are limited in their interpretation. Future research which explores, in particular, perceptions of father's and their children, could help in the illumination of further processes in relation to the concept of ADHD at a micro level and how this may possibly fit with the macro level of contextual implications for ADHD.

5.3.4 The role of medication

The use of medication was extensively discussed within the current study. Psychoactive medication is advocated within the NICE guidelines as part of a comprehensive programme of care including psychological, educational, and social measures (NICE 2009). Within the current study medication was consistently discussed as the active treatment for ADHD with educational and behaviour

management strategies being seen as ways of supporting the struggles associated with ADHD rather than directly addressing them. For example, the structure of school was indirectly identified as a social factor contributing to the problem. However it was perceived that the education system is rigid and unlikely to change. In addition, discourses of the importance of education and attainment appeared to serve to maintain the need for the child to 'fit in' to education. Therefore, attempts to increase teachers understanding of ADHD occured, rather than addressing factors within the education system. This appeared to reinforce the concept of ADHD as a medical disorder requiring medication. This concept is consistent with arguments that current practice in ADHD may divert away from addressing the difficulties from within social and psychological models (Radcliffe & Newness, 2005; Rowe, 2005; Rentoul, 1995). Professionals did describe an awareness of social and cognitive explanations of ADHD, such as, the impact of social exclusion on self-esteem and the need to increase self-control and problem solving skills. However, these concepts were rarely acknowledged as being able to address the identified problem. Therefore, by adopting a medical understanding of ADHD alternative ways of constructing children's behaviour are being lost, for example, seeing ADHD behaviours as alternative cognitive styles rather deficits (Cooper, 2001).

Whilst medication was portrayed in a positive manner within the study all the parents involved did express some dissatisfaction as medication 'wore off'. Following this medication was reframed as a way of 'helping' the situation which warranted further management approaches in conjunction. Thus, being referred to as a 'window of opportunity' by professionals. Without a diagnosis and medication, parents and professionals found alternative 'management' approaches futile. The current findings can be discussed in relation to research into the efficacy of medication. Again

controversy is present within research into ADHD medications. Many who oppose its use highlight inconsistencies in the research reports (Breggin, 2001; Baldwin, 2000). Such research highlights only short-term effectiveness of medication and questions their validity in reducing clinical presentations (Schachter, et al., 2001). The current study reflected the short-term nature of medication in temporarily relieving difficulties with behaviour whilst clinical features remained present. In addition, it was suggested that medication was often required until the child is no longer expected to adhere to the social demands of education. The need to 'increase' medication was also discussed and dissatisfaction with side effects, particularly loss of appetite and reduced physical growth were emphasised. Existing research also highlights these concerns (Baldwin, 2000, Radcliffe & Newness, 2005). Interestingly, the current study identified a belief that medication allowed an opportunity for different responses to children's behaviour, for example, positive attention, and praise. It was interpreted that the 'calming' effect of stimulant medication on children meant that parents, teachers, and professionals were able to highlight more positive behaviours in children, which according to social learning theory leads to increased display of positive behaviours in the child (Bandura, 1977). These findings could relate to Sandler, Glesne and Geller's (2008) study in which they attributed treatment benefits of open label placebo drug treatments to changes in parenting style. Therefore, the qualitative accounts of experiences of medication use in children may offer further insight into the active agent or causal factor in medication use. It may be that acknowledging the existence of a problem, and taking action towards managing it, is in itself an active ingredient in addressing problems. The sense that 'something is being done' appears to change parenting practice. The importance of changes to parenting practice in managing ADHD have been

documented (Dennis et. al. 2010; Deault, 2010; Singh, et al., 2010b; Dreyer et al., 2010; Bates, 2009; Bimble, 2009; Kenny and Blew, 2006; Johnstone & Mash, 2001).

Within the current study, the construction of ADHD appears to identify and explore specific discourses of parenting practice and behaviour management as a way of addressing the perceived difficulties. These discourses interact with the discourses discussed previously, predominantly relating to 'blame' and 'causation' and the perceived social need to attribute responsibility outside both the child and parent's control.

5.3.5 Toward a multimodal approach

The professionals in the current study all identified the recognition within research that medication in conjunction with behaviour management approaches is currently the most advocated management approach to ADHD (Bates, 2009; NICE, 2009). It was of notable interest that behaviour management approaches were only seen to be useful after a diagnosis of ADHD. In addition, there appeared to be some inconsistencies with the need for behaviour management strategies to be ADHD specific or based on 'usual' theories. As described in the current clinical guidelines behaviour management strategies took a group format and were based on social learning theories (Bandura, 1977). These approaches appeared to be most useful due to the sense of a *shared understanding* and specialist knowledge that was offered once a diagnosis had been received. Within the current study, it is suggested that 'investing in the *simple truth* of ADHD' facilitated this. Without an investment in ADHD, behaviour management strategies appeared consistent with blame to the parent or seeing a child as 'naughty'. Existing research suggests that whilst behavioural approaches to managing ADHD are likely to be useful, there appears to

be little concluding evidence as to their effectiveness (Bimble, 2009). Within existing research a number of factors are suggested which may prevent professionals, parents, and young people from engaging with such approaches (Johnstone & Mash, 2001; Deault, 2010; Dennis et al., 2008; Dreyer et al., 2010, Bimble, 2009). Such factors include the desire for a 'quick fix' and problematic family functioning. The current study offers insight into the need for families to gain a satisfactory understanding of the problem before they may engage with such strategies. This appears to be consistent with Bimble's (2009) suggestion that consistency between the home and school environment and parental co-operation are fundamental to the success of behaviour management approaches. In addition, Dreyer et al. (2010) identify parental stress as a perceived barrier to these strategies. High levels of stress were indeed present within all experiences in the current study and it was only when a diagnosis was given and medication commenced that there appeared to be relief in this. Findings from a study by Singh et al., (2010b) in relation to mindfulness training for parents may be relevant here, suggesting that personal transformations need to take place in order to promote positive outcomes. The current study suggests that multimodal approaches would need to be incorporated into social representations of ADHD in order to be more effectively utilised. In addition, the role of personal agency, and the self within a broad social context, would need to be reflected upon.

5.3.6 Reconstructing ADHD

It has been suggested that social discourses, most significantly facilitated by media, may account for how ADHD has been constructed within society (Danforth & Navarro, 2001; Norris & Lloyd, 2000). The current study appears to reflect similar experiences to those voiced in the media of parents at their 'wits end', 'in need of

specialist help' and experiencing 'relief that there is a medical problem,' as well as concerns over the 'stigma of poor parenting' which appeared to stem from social messages. These reports, all appear to add strength to the role of discourse in constructing the notion of ADHD as a medical condition. It appeared that these discourses continued to impact upon those within this study.

It has been suggested that research into ADHD should attempt to explore social and psychological understandings of ADHD. Within the current study awareness of environmental factors, as casual influences on children's behaviour was limited. The category '*social expectations*' identified some of the social factors, such as developmental norms, pressures to conform, the education system, and the role of the professional within society. These were reported to affect experiences rather than as the 'cause' of the perceived problem. However, existing research identifies a range of social and environmental factors that influence children's behaviour. Of note, Golding (2004) has suggested a link between attachment styles and 'ADHD' like behaviours. Within the current study, there were a small number of references to the role of 'attachment' within ADHD. This was viewed as a factor in the struggle to cope rather than an explanation for children's behaviour. In addition, one of the professionals interviewed attributed difficulties in parent-child attachment as an underlying factor in ADHD that was seen to reduce the effectiveness of medication. This led to the interpretation that the issue of 'ADHD' as a brain disorder became more pressing than 'underlying' explanations. In addition, alternative explanations were described as harder to address. Whilst these observations may be of interest, the role of attachment was not fully explored within this research process. Throughout

the current research, stress within families, busy lives, and social concerns over the need for comparison, regulation, and control were consistently reported. However, they were again seen as a consequence of experiences of ADHD rather than being able to account for the existence of perceived problems.

5.4 Conclusions

Limited research exists which explores the social, cultural, and environmental context of ADHD practice. A review of existing literature identified debates and controversies regarding its diagnosis and management. The current NICE guidelines call for a multi-modal approach to ADHD, and identify the importance of social and psychological interventions to influence practice. However, the presence of a dichotomy between views of ADHD as a medical or cultural construct remained evident in research.

To further explore these issues and address the imbalance of current research a constructivist version of grounded theory methods was adopted within the present research. This is ultimately a humanistic view that invites reflection and empowers the researcher to explore alternative understandings of a phenomenon. The meanings, beliefs, context, and processes, constructed both within and between people, were explored within this research.

The current research produced a thorough exploration of experiences of ADHD. A model of '*investing in ADHD*' emerged in which those involved were seen to invest energy and resources in the construction of the '*simple truth*' of ADHD. This was interpreted as an acceptance of the dominant medical discourse of ADHD and was

seen to contribute to social constructions of ADHD. It is argued within the current research review that a wider cultural acceptance of this discourse is also adopted. In conclusion, whist the current investment in the '*simple truth'* of ADHD appeared to hold the most meaning for those involved in the study, this position also appeared to limit engagement with alternative understandings of ADHD and therefore management options. The current position of ADHD can be seen to be socially created through discourses, which are socially and culturally formed. Such discourses are predominantly around expectations for 'childhood' and 'parenthood' and the conflicts which arise from the perceived problem with children's behaviour.

5.5 Contributions to Clinical Practice

In exploring the experiences of the diagnosis and management of ADHD, an understanding has emerged of the social and psychological processes that contribute to its construction. These processes are now discussed in relation to their contributions to the clinical practice of Counselling Psychology.

Counselling psychology is underpinned by a humanistic ethos which values the primacy of the individual's experience. Therefore, Counselling Psychologists place emphasis on the therapeutic relationship and the individual's ability and desire for self-reflection, which in turn requires personal autonomy and choice. Counselling Psychologists are increasingly being employed within CAMHS settings. Such practice poses challenges for practitioners who wish to utilise the therapeutic relationship and engage in an individual's understanding. When working with this client group the therapist requires insight into the child's developmental capacity and an appreciation of the social systems, which may limit personal autonomy or impact on the child's development and personal value system. Tensions can arise when

expectations of the ‘child in therapy’ are not in line with realistic expectations of the afore mentioned issues. Counselling Psychologist’s working with the CAMHS population are thus both ideally placed to engage children, young people, and families, whilst also facing the challenges of working therapeutically within this population. In relation to ADHD, current literature appears to suggest that the Psychologists role is relatively limited, placing emphasis on the role of medical professionals in diagnosing and managing such problems. Current practice guidelines suggest that diagnostic and management approaches to ‘ADHD’ should be multi-disciplinary (NICE, 2009). Within the current research there appeared to be many opportunities to utilise the skills of a wider range of professionals, including Counselling Psychologists. This offers a number of opportunities to contribute to clinical practice and findings will have particular interest for Counselling Psychologist working with children and families. In particular, the philosophical stance of the current understanding of ADHD as formed through social discourse can be seen to offer valuable opportunities for Counselling Psychologists in this clinical area.

The current research suggests that an appreciation is required of the struggles families have encountered in the identification of their child’s behaviour problem and the personal conflicts and societal pressures that may contribute to them seeking a diagnosis. This suggests that there may be a need for Counselling Psychologist’s to utilise the therapeutic alliance as an opportunity to engage with families in meaningful ways. This draws upon the importance of an appreciation of the child’s context, in particular the family system. Children and young people lack the personal autonomy and developmental ability to identify personal aspirations, the desire for

change, and the ability for independence from the family system. Therefore, by utilising Counselling Psychologists in effective therapeutic relationships within the family system may perhaps assist in their desire to feel understood and ultimately engage in ways of exploring and addressing the underlying social and psychological difficulties associated with ADHD. This may enable those involved to engage in narratives and discourse that prioritise multi-modal approaches, consequently fostering effective engagement with behaviour management groups. This would require adequate promotion of engagement in parenting groups at the lower two tiers of the CAMHS four-tier strategic framework (Health Advisory Report, 1995). Counselling Psychologists could offer a valuable role in direct clinical work and providing consultation to professionals working within these tiers. Such consultation could focus on supportively challenging discourses which seek to promote engagement in medical orientations to children's behaviour.

In addition, from a social constructionist viewpoint, a number of discourses can be seen to potentially contribute to constructs of ADHD and perhaps limit management options. The current research suggests that alternative explanations of ADHD may not currently offer meaning to those involved in the study. However, a review of existing literature suggests that a more varied view of ADHD incorporating both social and psychological models of understanding may offer more opportunity to engage families in a comprehensive programme of care. Therefore, there appears to be the requirement for ADHD research to filter through to current practice. Counselling Psychologist, whose practice is rooted in both humanistic psychology and behavioural science, may be able to support families and professionals to explore alternative narratives and deconstruct the notion of 'ADHD'. Such practice would

need to be mindful of the sense of 'helplessness' and disempowerment this approach may initially create.

Finally, the current research could be seen to add strength to the need for psychological knowledge and support in the implementation of behaviour management programmes. Existing literature suggests a number of barriers exist to a meaningful engagement with such approaches. The current research highlighted the dominance of the medical construct of ADHD as possibly contributing to these barriers and limiting management options. Therefore, the increased presence of more social and psychological models of understanding may be helpful in engaging families in behaviour management programmes earlier. This may help engagement of management approaches which directly address some of the social and psychological factors which influence underlying causes of children's difficult to manage behaviours. Direct clinical work should draw upon developing holistic psychological formulations of the presenting problems and consequently develop care plans which address the underlying social and psychological aspects of ADHD. Such work may be of benefit at an early intervention stage.

5.6 Limitations of the research

Debates exist as to whether concepts that emerge from grounded theory methodology are descriptive or explanatory (Willig, 2001). The current study can be seen to contribute to explanations of ADHD that have emerged from one set of experiences. This identifies the limitations of the current study in extending to other contexts and informants. However, within the methodology employed this is also likely to give strength to the in depth and meaningful understanding of this set of experiences.

A further limitation of the study is that the two young people interviewed were very different in age. It should be considered that the period of adolescence itself identifies specific issues around ADHD than pre-adolescent children. In addition, one of the young people interviewed had a co-morbid diagnosis of OCD, which would have influenced their experience. However, within the current methodology this variance is likely to have given strength to the analytical process. In addition, concerns regarding generalisation should not be projected onto qualitative methods of research which are concerned with meaning of experiences rather than the ability to replicate findings. Therefore, whilst caution is sought in transferring the current findings across all experiences of ADHD, it is likely that this enhances rather limits the current research findings. As Charmaz (2006) suggests concern with generalisation serves to decontextualize the construction of theory whilst constructivist grounded theory methods require interpretive and contextualised analysis.

A further limitation of the current study can be highlighted in relation to theoretical sampling techniques. Charmaz (2006) suggests that theoretical sampling means seeking data which is pertinent to developing the emerging theory. As such theoretical sampling allows the researcher to return to the research field and identify new data, including research participants, which will elaborate and refine categories, this may include negative case analysis. The current study failed to engage in theoretical sampling to the extent of returning to the field until saturation. This was due in part to time constraints and to difficulties in managing the amount of data that this can produce. In addition, ethical considerations, time constraints and length of time taken to get ethical approval, were all issues that restricted the ability to recruit

participants in accordance with emerging concepts. Perhaps most importantly this process could be seen to have been restricted by the lack of variance within the research setting. For example, attempts to explore alternative understandings of ADHD were restricted through a lack of non-medical perspectives to ADHD within the research site.

Finally, Hayes (1998) suggests that there is lack of clarity as to what constitutes a complete theory. The current research stems from a social constructionist approach, which assumes that multiple realities exist, and therefore does not claim a complete theory. Consequently, the presented theory should be viewed as tentative and mobile in accounting for processes within the practice of ADHD. However, the constructivist nature of the research has allowed analysis to retain a clear connection with both the data and context. In addition, the emerging theory was felt to resonate with supervisors.

5.7 Implication for Future Research

Charmaz (2006) suggests that studies involving grounded theory methods can extend, contribute to, and at times divide existing knowledge on an area of phenomenon. The current study can be seen to offer an in-depth exploration of the experiences of those involved in the study. This offers a number of implications for future research that could further contribute to the knowledge of ‘ADHD’ and its associated practice.

In general, research that explores social and psychological explanations of ADHD is likely to extend knowledge within ADHD and bridge the gap with positivist enquiries of ADHD. Following on from the current study, research is required, which explores experiences of individuals who have adopted a non-medical understanding of the perceived problem. This may further extend the emerging theory and offer greater insight into the construction of ADHD.

Finally, the current study identified the lack of research in relation to fatherhood and ADHD and the lack of presence of fathers in qualitative research in general. Fatherhood is likely to offer insight into the construction of meaning within ADHD. Research, which seeks to explore father's experiences of ADHD, may contribute to new knowledge and understanding in this area.

5.8 Reflection

Within grounded theory methodology, the role of existing theory is debated. Glaser and Strauss (1967) suggest that the research should avoid preconceived ideas that develop through literature searching. However, within constructivist versions of grounded theory an appreciation of any preconceptions of the researcher and knowledge of the phenomenon at study are built into the research process rather than denied. Within the current study, my position as a trainee Counselling Psychologist and practitioner within Tier 2 CAMHS was acknowledged. Throughout the study, I attempted to engage with a number of different perspectives that exist within the literature around ADHD. I initially decided to engage within Tier 3 CAMHS services with the view that the cyclical nature of grounded theory methods may guide the research to examine the variety of existing discourses. However, upon reflection this

did not appear to emerge. I was surprised that services placed within third sector service provision adopted a similar position to health care services and that those who adopted alternative positions did not feature within the study. The aim of this research was to illuminate the social and psychological processes that influence individual experiences of ADHD. As such, the research does not dispute the existence of 'ADHD' as a problem within society but contributes to an understanding of why 'ADHD' exists in its current state and how it may be constructed through social discourses. By remaining engaged with this stance, I was able to manage the tensions within the research process and remain open to no one position being privileged. My position as researcher is further considered within the following critical appraisal of the research process.

6 Critical Appraisal

This section provides a reflexive critical appraisal of the research process and the challenges faced.

6.1 Commencing the research

My initial research objective emerged from my interest in the area of children's emotional wellbeing and my desire to understand children and families within the social context they are situated. During my time as a trainee counselling psychologist I faced challenges in clinical experiences with families who present with difficulties associated with children's externalised behaviour. I personally found families difficult to engage within a psychological model. Working within the NHS I became aware of the prominence of medical professionals and the trust families placed in healthcare services. The presence of discourses around ADHD within society is widely prominent. Upon engaging with the academic literature on ADHD, back in 2008, I was struck by the existence of two opposing debates. I became concerned with the preoccupation with the causes of ADHD and academic debates around whether or not it 'exists'. In addition, I was interested to note that research, which adopted a psychological perspective to ADHD, was limited and offered little utility in practice. Therefore, I began to consider the importance of such research within both the academic arena and within clinical practice.

In my original research design, I formed my overarching aim to explore the experiences of professionals, parents, and children in order to develop an understanding of the current diagnosis and treatment of ADHD within the National Health Service (NHS). Secondly, I chose to adopt a grounded theory approach,

which it was envisaged would go beyond description in which theory may emerge that could contribute to an understanding of how ADHD can be viewed within the social, cultural and environmental contexts in which they occur. It was this second point, which led me to adopt a constructivist approach to the research analysis at a later stage. Initially, I was concerned with limiting my engagement with the existing literature, which can be viewed as influencing the researcher's engagement with the phenomenon of study and reducing the grounded nature of the analysis (Glaser & Strauss, 1967). However, the further I engaged with constructivist versions of grounded theory, the more I acknowledged my position within the research process. Therefore, the importance of reflexivity was valued and intrinsic to the production of the theoretical model.

6.2 Gaining approval and access to healthcare services

The challenges faced within the study were at times due to the adoption of a qualitative approach within a medical context. In applying to conduct research and constructing a proposal, the relevant committee bodies require prior information regarding the nature of the study and the expected outcomes. Within a qualitative framework, particularly grounded theory methods, the development of the research becomes progressively focused. For the purpose of the academic research committee, this is implicitly accepted. In contrast, I found the NHS trust research approval much more rigid and less focused on qualitative methodology. Throughout the NHS approval process, I was required to predetermine my research process instead of allowing it to remain flexible, for example, the number of and ages of participants, the length of time for interviews and the number of interviews taking place with each participant. Upon reflection, this may have served to narrow my research process as I

became concerned with predefining my participant sample and analytical approach. At times, I felt I was carrying out research in juxtaposition to the medical orientation of the health care system. This is highlighted, by the NHS trust's requirement for guidance from a 'specialist' in ADHD; this was stipulated to be a Child Psychologist from within the trust. At times, I had to struggle to remain focused upon the qualitative nature of the research, and to defend my research against the issues of 'scientific rigour' that pertain to quantitative approaches. The process of NHS trust approval raised considerations of the concept of 'gatekeepers' to care in which those in power could be seen to *control* and monitor access to health care resources and in conducting research. In contrast, the NHS ethics committee gave positive feedback on my approach to the research topic and ethical considerations, particularly the importance of the child's voice within research.

6.3 Engaging with participants

As I started to engage with participants, I was aware of a strong tendency to place ADHD within the concern of medical professionals, particularly Psychiatrists. I had invited a number of Psychologists to take part, none of which responded. The trust appointed Psychiatrist overseeing the project, informed me that Psychologists do not have specialist experience of ADHD. I began to wonder if the issues of power discussed previously, could be seen to impact upon clinical practice. In an attempt to engage in a theoretical sampling approach within grounded theory, I wanted to explore alternative perspectives to ADHD, which may offer further insight. I applied for further ethical approval to recruit participants from a service situated within the voluntary services sector, which had been referred to within all of my previous interviews. I hoped this would allow me to explore alternative voices within ADHD

practice. Whilst each experience is unique, it emerged that a similar importance within this service was placed upon the 'medical professional.' However, this service was situated outside of the NHS and aimed to provide social and psychological interventions and support for families. Therefore, I was interested to note the implicit acceptance of the medicalisation of the problem.

Initially, I was struck by the sense of helplessness individuals expressed when talking about ADHD. Upon reflection, I became aware of how these emotional responses applied to my own clinical experiences of similar problems. However, as I engaged further with these stories, voices of hope and support stemming from within the current practice of ADHD emerged. My position as both researcher and practitioner are of particular importance here. Within my clinical practice as a 'practitioner' and throughout my training, I value the importance of listening to individual experience. Indeed, within Counselling Psychology the humanistic underpinning places emphasis on the therapeutic relationship and the subjective perspective of the individual (Strawbridge & Woolfe, 2003). This stance encourages the practitioner to 'respect first person accounts as valid in their own terms' (BPS, 2000 cited in Strawbridge & Woolfe, 2003, pp.11). Therefore, within clinical practice I attempt to listen to individual's experience and help them find meaning from within this. Upon reflection, I realised I was becoming focused on reporting an accurate portrayal of the participant's lived experience as I felt they wished it to be heard. However, this can be seen in contrast to the grounded theory researcher's attempts to conceptualise latent patterns (Glaser, 2007). Therefore, throughout the research process I struggled to manage the competing roles of practitioner and researcher.

6.4 Managing the competing roles of researcher and practitioner

Within the context of a clinical setting, particularly the NHS it can be difficult to resist the biomedical model, which exists in such organisations and settings. I became aware of the dilemmas of resisting this model throughout my research process. I became focused on participant's descriptions of ADHD that stemmed from biological accounts of the problem. In my desire to understand individual experience, I did at times become absorbed in such realist accounts. This position at times became overwhelming, in listening to participants real life struggles with their perceived difficulties and how they had engaged in futile attempts to understand the problem, I became absorbed in the positions adopted by those interviewed. For example, I too began to see the value in constructing a biological account of ADHD in order to make sense of the difficulties. Following a meaningful engagement with those interviewed I became aware of the contentions and distress caused by perceived 'opposition' to the diagnosis. Thus, I became concerned with avoiding to discount their adopted position, which may have been further impacted upon by my professional proximity to the services involved. I found that an engagement with a social constructionist stance required a great deal of cognitive investment and at times created more questions than 'answers'. At times the overwhelming nature of the participants accounts and tensions in my own personal and professional life, led me to seek more 'concrete' and 'realist' understandings of the problem. This may also have been in an attempt to legitimise participant's stories.

I was at times explicitly aware of the tensions of my role as researcher and practitioner. This can be illustrated, when following a parent's particularly overwhelming and emotional description of her dilemmas of medicating her child;

she described wishing that there were an alternative to this option, but having been told that no other alternative existed. I felt a rising struggle to resist my 'practitioner' role of helping the parent to explore alternative ways of managing her situation. Whilst I found this difficult, I was able to draw upon my awareness of the need to remain within the ethical boundaries of my role as 'researcher'. Following the interview when the parent asked me if there was an alternative, I highlighted my role as researcher and suggested that she discuss her child's care with her health practitioner. As I reflected on this, I considered how my boundaries between the two roles might have been different. For example, had the parent become increasingly distressed would I have drawn upon my role as practitioner to support her? Indeed as a researcher, I was drawing upon therapeutic skills of building trust and rapport, similar to the therapeutic relationship. It was through this encounter that I became more aware of the intrinsic nature of my professional practice and the philosophical underpinnings of my training within the research process.

The strength of Counselling Psychology in engaging in reflective practice allowed me to manage these tensions. In acknowledging my position, I was able to utilise this reflection to support my analysis and further explore latent patterns within the data. I began to view myself as a social actor within the construction of ADHD. I too was responding to participant's voices of the 'investment in ADHD'. In positioning myself as 'within' and 'contributing to' constructions of ADHD, I was able to explore the data from this perspective. I engaged with questions, such as, what it meant for me to invest in this position, and what these accounts of ADHD had offered me as a researcher. The emerging theory is therefore, constructed through my

engagement with the lived experiences and an appreciation of the context of the research.

6.5 Conclusions

The difficulties encountered in managing my competing roles as practitioner and researcher can be aligned with the tensions between biomedical, sociological, and psychological models of understanding ADHD. Each of these models holds implicit philosophical underpinnings relative to what constitutes 'scientific knowledge.' Counselling Psychology's roots within humanistic and existential- phenomenological psychology and experimental behavioural science hold meaning in the psychologist's identity as a 'scientist-practitioner'. In adopting a grounded theory approach, the importance of clear conceptual frameworks was also imperative. Grounded theory methodology can be seen to span across a number of epistemological positions, including realist and social constructionist versions. The assumption that concepts are constructed through lived experience rather than 'discovered' was engaged in this study. Whist this allowed the research to be reflexive in nature, tensions emerged which related to how these voices were listened to. From my professional view the previous difficulties faced in clinical experiences of 'ADHD' have been somewhat legitimised by the strength of the current research in positions of '*investing in ADHD.*' In which, individuals investment to maintain the construction of ADHD as pertaining to a biomedical model appears to limit a comprehension of alternative explanations. Therefore, current practice appears to restrict the application of social and psychological models of understanding ADHD.

The aim of this critical reflection was to illuminate the interpersonal aspects of the research process from my position as researcher. The difficulties and tensions faced within the research give further insight into how these perspectives shaped the research process. I commenced the research by identifying the opposing views that exist with ADHD research and practice. Whilst the research process seemed to engage with only one position of this dichotomy, a clear understanding has emerged of how this position is constructed and how it serves an important function in families experiences of the difficulties associated with ADHD. Furthermore, the social and psychological processes that contribute to this position have been described within an emerging theoretical model. Qualitative data analysis can never be free from interpretation and as such, all qualitative analysis is constructed through the researcher's perspective. For me as a grounded theory researcher I became concerned with listening to whatever is voiced within the data. I was then able to explore and reflect upon the contextual productions of these voices.

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APPENDICES

Appendix 1

Notes for contributors

Manuscripts (by invitation only), in triplicate and in English, and editorial inquiries should be
submitted to the Editors:
Ronald J. Prinz, Ph.D.
Department of Psychology
University of South Carolina
Columbia, South Carolina 29208
e−mail: prinz@sc.edu
Thomas H. Ollendick, Ph.D.
Department of Psychology
Virginia Polytechnic Institute and State University
Blacksburg, Virginia 24061−0355
e−mail: tho@vt.edu
Contributions are by invitation only. Suggestions for topics and potential authors are welcome and
should be submitted to the Editors.
1.
Submission is a representation that the manuscript has not been published previously and is not
currently under consideration for publication elsewhere. A statement transferring copyright from the
authors (or their employers, if they hold the copyright) to Plenum Publishing Corporation will be
required before the manuscript can be accepted for publication. The Editors will supply the necessary
forms for this transfer. Such a written transfer of copyright, which previously was assumed to be
implicit in the act of submitting a manuscript, is necessary under the U.S. Copyright Law in order for
the publisher to carry through the dissemination of research results and reviews as widely and
effectively as possible.
2.
Type double−spaced on one side of 8−1/2 × 11 inch white paper using generous margins on all sides,
and submit the original and two copies (including copies of all illustrations and tables). All copies
must be dark, sharp, and clear. Computer−generated manuscripts *must* be of letter quality (*not*
dot−matrix).
3.
A title page is to be provided and should include the title of the article, author‘s name (no
degrees), author‘s affiliation, and suggested running head. The affiliation should comprise the
department, institution (usually university or company), city, and state (or nation) and should be typed
as a footnote to the author‘s name. The suggested running head should be less than 80
characters (including spaces) and should comprise the article title or an abbreviated version thereof.
For office purposes, the title page should include the complete mailing address, telephone number, fax
number, and e−mail address of the one author designated to review proofs.
4.

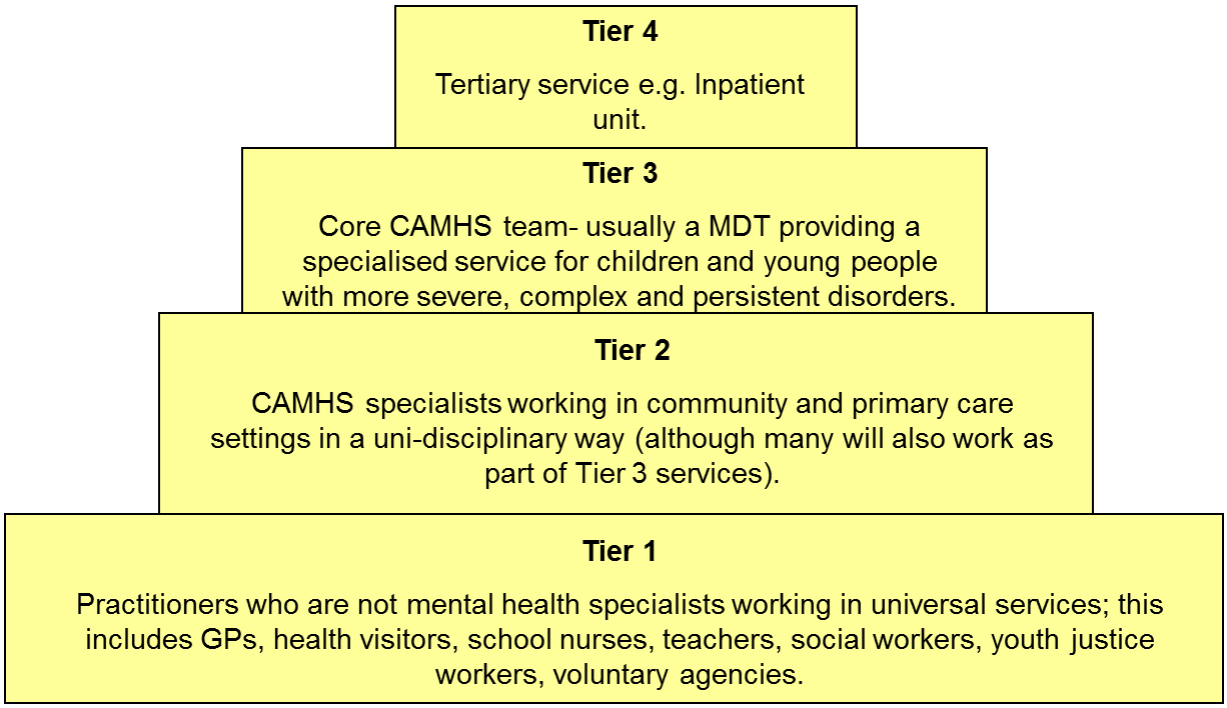
1
5. An abstract is to be provided, preferably no longer than 100−200 words.
A list of 4−5 key words is to be provided directly below the abstract. Key words should express the
precise content of the manuscript, as they are used for indexing purposes.
6.
All acknowledgments (including those for grant and financial support) should be typed in one
paragraph (so−headed) on a separate page that directly precedes the References section.
7.
Tables should be numbered (with Arabic numerals) and referred to by number in the text. Each table
should be typed on a separate sheet of paper. Center the title above the table, and type explanatory
footnotes (indicated by superscript lowercase letters) below the table.
8.
Illustrations (photographs, drawings, diagrams, and charts) are to be numbered in one consecutive
series of Arabic numerals. The captions for illustrations should be typed on a separate sheet of paper.
All illustrations must be complete and final, i.e., camera−ready. Photographs should be large, glossy
prints, showing high contrast. Drawings should be high−quality laser prints or should be prepared
with india ink. Either the original drawings or good−quality photographic prints are acceptable.
Artwork for each figure should be provided on a separate sheet of paper. Identify figures on the back
with author‘s name and number of the illustration. Electronic artwork submitted on disk should
be in the TIFF or EPS format (1200 dpi for line and 300 dpi for half−tones and gray−scale art). Color
art should be in the CYMK color space. Artwork should be on a separate disk from the text, and hard
copy ***must*** accompany the disk.
9.
List references alphabetically at the end of the paper and refer to them in the text by name and year in
parentheses. References should include (in this order): last names and initials of *all* authors, year
published, title of article, name of publication, volume number, and inclusive pages. The style and
punctuation of the references should conform to strict APA style−illustrated by the following examples:
Journal Article
Romano, J. M., Turner, J. A., & Jensen, M. P. (1997). The family environment in chronic pain
patients: Comparison to controls and relationship to patient functioning. *Journal of Clinical Psychology in Medical Settings, 4,* 383−395.
Book
Schlinger, H. D., Jr. (1995). *A behavior analytic view of child development.* New York: Plenum Press.
Contribution to a Book
Daugherty, T. K., & Shapiro, S. K. (1994). Behavior checklists and rating forms. In T. H. Ollendick,

N. J. King, & W. Yule (Eds.), *International handbook of phobic and anxiety disorders in children and*
adolescents (pp. 331−347). New York: Plenum Press.
10.
Footnotes should be avoided. When their use is absolutely necessary, footnotes should be numbered
consecutively using Arabic numerals and should be typed at the bottom of the page to which they
refer. Place a line above the footnote, so that it is set off from the text. Use the appropriate superscript
numeral for citation in the text.
11.
In general, the journal follows the recommendations of the 1994 *Publication Manual of the American*
Psychological Association (Fourth Edition), and it is suggested that contributors refer to this publication.
12.
After a manuscript has been accepted for publication and after all revisions have been incorporated,
manuscripts should be submitted to the Editor‘s Office as hard copy accompanied by electronic files on disk. Label the disk with identifying information −− software, journal name, and
first author‘s last name. **The disk *must* be the one from which the accompanying manuscript (finalized version) was printed out**. The Editor‘s Office cannot accept a disk
without its accompanying, matching hard−copy manuscript.
13.
The journal makes no page charges. Reprints are available to authors, and order forms with the
current price schedule are sent with proofs.
14.
Author Instructions Clinical Child and Family Psychology Review
2
Springer Open Choice. In addition to the normal publication process (whereby an article is submitted to the journal and access to that article is granted to customers who have purchased a
subscription), Springer now provides an alternative publishing option: Springer Open Choice. A
Springer Open Choice article receives all the benefits of a regular subscription−based article, but in
addition is made available publicly through Springers online platform SpringerLink. To publish via
Springer Open Choice, upon acceptance please visit www.springeronline.com/openchoice to complete
the relevant order form and provide the required payment information. Payment must be received in
full before publication or articles will publish as regular subscription−model articles. We regret that
Springer Open Choice cannot be ordered for published articles.
15.
Author Instructions Clinical Child and Family Psychology Review
3http://www.springer.com/journal/10567

Appendix 2
Outline of the four-tier CAMHS framework

CAMHS four-tier strategic framework

Health Advisory Report (1995)



Appendix 3

Copies of Res 20b form for RHIS

UNIVERSITY OF WOLVERHAMPTON

RES 20B
(October 2003)

School of Applied Sciences Ethics Committee: submission of project for approval

To be completed by SEC:
Date Received: Project No:

- **This form must be word processed – no handwritten forms can be considered**
- **ALL sections of this form must be completed**
- **No project may commence without authorisation from the School Ethics Committee**

CATEGORY B PROJECTS:

There is identifiable risk to the participant's wellbeing, such as:

• significant physical intervention or physical stress.
• use of research materials which may bring about a degree of psychological stress or upset.
• use of instruments or tests involving sensitive issues.
• participants are recruited from vulnerable populations, such as those with a recognised clinical or psychological or similar condition. Vulnerability is partly determined in relation to the methods and content of the research project as well as an *a priori* assessment.

All Category B projects are assessed first at Divisional level and once approved are forwarded to the School Ethics Committee for individual consideration. Undergraduates are not permitted to carry out Category B projects.

Title of Project:	A grounded theory approach to understanding the current diagnosis and treatment of Attention Deficit Hyperactivity Disorder (ADHD) within the National Health Service (NHS).
Name of Supervisor: (for all student projects)	Dr John Bergin
Name of Investigator(s):	Lucy Wheen
Location of Research: (Module code, MPhil/PhD, Staff)	PS5011 Practitioner Doctorate Counselling Psychology Thesis
Qualifications/Expertise of the investigator relevant to the submission:	BSc (Hons) Psychology and Postgraduate Certificate in Primary Care Mental Health Interventions. The researcher is currently employed in a Primary care Mental Health Service for Children and Young People (0-19 years old) and has been for a duration of 2 years.

Participants: Please indicate the population and number of participants, the nature of the participant group and how they will be recruited.	Participants will be recruited from a Child and Adolescent Mental Health Service in the NHS Trust within which the researcher is employed. This will be a Child and Family Service in the North West of England. The researcher works in liaison with, but not directly within, the service and therefore does not have clinical responsibility for any of the possible participants. The sample will be 4 professionals, 4 parents and 4 children and young people between the ages of 8 and 16 who have been diagnosed with ADHD. Possible participants will be identified through the service's current patient database and recruited via letter.

Continued overleaf
Please attach the following and tick the box provided to confirm that each has been included:

Rationale for and expected outcomes of the study	**x**
Details of method: materials, design and procedure	**x**
Information sheet* and informed consent form for participants **to include appropriate safeguards for confidentiality and anonymity*	**x**
Details of how information will be held and disposed of	**x**
Details of if/how results will be fed back to participants	**x**
Letters requesting, or granting, consent from any collaborating institutions	
Letters requesting, or granting, consent from head teacher or parents or equivalent, if participants are under the age of 16	**x**
Is ethical approval required from any external body? YES **If yes, which Committee?** Local NHS Ethics Committee *NB. Where another ethics committee is involved, the research cannot be carried out until approval has been granted by both the School committee and the external committee.*	

Signed: _____ Date: .....
(Investigator)

Signed: _____ Date: .....
(Supervisor)

Except in the case of staff research, all correspondence will be conducted through the supervisor.

FOR USE BY THE SCHOOL ETHICS COMMITTEE

Divisional Approval Granted: _____ Date:
(Chair of Divisional Ethics Committee)

School Approval Granted: _____ Date .....
(Chair of School Ethics Committee)

UNIVERSITY OF WOLVERHAMPTON

RES 20B
(October 2003)

School of Applied Sciences Ethics Committee: submission of project for approval

To be completed by SEC:

Date Received:
Project No:

- **This form must be word processed – no handwritten forms can be considered**

- **ALL sections of this form must be completed**
- **No project may commence without authorisation from the School Ethics Committee**

CATEGORY B PROJECTS:

There is identifiable risk to the participant's wellbeing, such as:

• significant physical intervention or physical stress.
• use of research materials which may bring about a degree of psychological stress or upset.
• use of instruments or tests involving sensitive issues.
• participants are recruited from vulnerable populations, such as those with a recognised clinical or psychological or similar condition. Vulnerability is partly determined in relation to the methods and content of the research project as well as an *a priori* assessment.

All Category B projects are assessed first at Divisional level and once approved are forwarded to the School Ethics Committee for individual consideration. Undergraduates are not permitted to carry out Category B projects.

Title of Project:	A grounded theory approach to understanding the current diagnosis and treatment of Attention Deficit Hyperactivity Disorder (ADHD).
Name of Supervisor: (for all student projects)	Dr John Bergin
Name of Investigator(s):	Lucy Fearns
Location of Research: (Module code, MPhil/PhD, Staff)	PS5011 Practitioner Doctorate Counselling Psychology Thesis
Qualifications/Expertise of the investigator relevant to the submission:	BSc (Hons) Psychology and Postgraduate Certificate in Primary Care Mental Health Interventions. The researcher is currently employed in a Primary care Mental Health Service for Children and Young People (0-19 years old) and has been for a duration of 2 years.

Participants: Please indicate the population and number of participants, the nature of the participant group and how they will be recruited.	Participants will be recruited from a Child and Adolescent Mental Health Service in the NHS Trust within which the researcher is employed. This will be a Child and Family Service in the North West of England and the user led charity service, [redacted]. The researcher works in liaison with, but not directly within, the service and therefore does not have clinical responsibility for any of the possible participants. The sample will be 4 professionals, 4 parents and 4 children and young people between the ages of 8 and 16 who have been diagnosed with ADHD. Possible participants will be identified using a snowball sampling technique.

Continued overleaf
Please attach the following and tick the box provided to confirm that each has been included:

Rationale for and expected outcomes of the study	
Details of method: materials, design and procedure	
Information sheet* and informed consent form for participants **to include appropriate safeguards for confidentiality and anonymity*	**x**
Details of how information will be held and disposed of	

Details of if/how results will be fed back to participants	
Letters requesting, or granting, consent from any collaborating institutions	
Letters requesting, or granting, consent from head teacher or parents or equivalent, if participants are under the age of 16	
Is ethical approval required from any external body? **If yes, which Committee?** *NB. Where another ethics committee is involved, the research cannot be carried out until approval has been granted by both the School committee and the external committee.*	

Signed: _____ Date: .....
(Investigator)

Signed: _____ Date: .....
(Supervisor)

Except in the case of staff research, all correspondence will be conducted through the supervisor.

FOR USE BY THE SCHOOL ETHICS COMMITTEE

Divisional Approval Granted: _____ Date:
(Chair of Divisional Ethics Committee)

School Approval Granted: _____ Date .....
(Chair of School Ethics Committee)

Appendix 4

Copies of NHS research approval letters

NHS
National Research Ethics Service
[redacted] Research Ethics Committee
[redacted]
Telephone: [redacted]
Facsimile: [redacted]

07 May 2009

Miss Lucy Wheen
Primary Child and Adolescent Mental Health Worker
Bury Primary Care Trust
Primary Care Mental Health Service
[redacted]

Dear Miss Wheen

Full title of study: **A grounded theory approach to understanding the current diagnosis and treatment of Attention Deficit Hyperactivity Disorder (ADHD) within the National Health Service (NHS).**
REC reference number: **09/H1006/29**

The Research Ethics Committee reviewed the above application at the meeting held on 30 April 2009. Thank you for attending to discuss the study.

Discussion:

In discussion, the Committee noted the following ethical issues.

The Committee was pleased that consent would be taken from both the child and the parent / guardian.

The Committee agreed that the PIS was well worded for each of the different age levels.

The Committee queried why the G.P was being informed.

The Committee did not think referring to a child as a *'case'* on the parents' PIS was appropriate.

The Committee noted that the PIS referred to *'parents'* however agreed this should be modified as some children may only have one parent or may have a legal guardian instead.

The Committee queried whether Appendix 6 was misleading as it mentioned *'an understanding of ADHD from people within the National Health Service'*.

The Committee agreed the PIS should make clear that data will be retained in this study.

The Committee agreed that explicit consent was required for audio recordings and initial boxes should be added to the consent form.

Discussion with Researcher:

The Committee thanked you for attending the meeting and the following points were raised: -

The Committee informed you that the application was well written and it was pleased that consent would be taken from the child and the parent. The Committee also praised you for the quality of the PIS for younger children.

The Committee informed you that the PIS should make clear that any data collected would still be used if a participant had withdrawn from the study.

You clarified that if the participant withdrew before the data was analysed then the data would be destroyed.

The Committee informed you that this needs to be made clear in the PIS.

The Committee informed you that the PIS for parents read as if they were part of the NHS and agreed it should be changed. Also, the Committee informed you that the child should not be referred to as a *'case'*.

You agreed.

The Committee informed you that some children might not have two parents and the PIS should be altered to reflect this.

You agreed.

The Committee informed you that the consent form should be altered to have a box to add the participants' initials and also that specific consent was required to tape record the interview and to use anonymous quotations.

You agreed.

You informed the Committee that you had been asked to seek an ADHD specialist to participate as a supervisor in the research. You asked if the Committee could suggest anyone.

The Committee informed you that it did not have anyone suitable but suggested seeking advice from the CAMS team as they would have experience in this field.

The Committee advised you to add a contact telephone number to the PIS in case a participant has any issues.

Decision – Favourable Opinion

The members of the Committee present gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation, subject to the conditions specified below.

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

1. A sentence should be added to the PIS informing the participant that if they withdraw from the study any data collected will still be used unless they withdraw before the data has been analysed.
2. Appendix 6 should be altered so the parent's child is not referred to as a case and the reference to National Health Service is removed.
3. The PIS should be altered to reflect the fact that a child may have only one parent or a legal guardian.
4. The consent form should request the initials of the participant and a sentence should be added seeking consent to use anonymous quotations and to record the interview.
5. A contact number should be added to the PIS.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission at NHS sites ("R&D approval") should be obtained from the relevant care organisation(s) in accordance with NHS research governance arrangements. Guidance on applying for NHS permission is available in the Integrated Research Application System or at http://www.rdforum.nhs.uk.

Approved documents

The documents reviewed and approved at the meeting were:

Document	*Version*	*Date*
Covering Letter	1	23 March 2009
Application	2.0	23 March 2009
Investigator CV	L. Wheen	23 March 2009
Investigator CV	J. Bergin	24 March 2009
Investigator CV	Y. Lewis	23 March 2009
Letter from Sponsor	1	24 March 2009
Statement of Indemnity Arrangements	1	24 March 2009
Protocol	1	23 March 2009
Interview Schedules/Topic Guides	1 - Appendix 1	23 March 2009
Letter of invitation to participant	1 - Appendix 3 (Professionals)	23 March 2009
Letter of invitation to participant	1 - Parents, children and young people	23 March 2009
Participant Information Sheet: PIS for Professionals	1- Appendix 5	23 March 2009

Participant Information Sheet: PIS for Parents	1 - Appendix 6	23 March 2009
Participant Information Sheet: PIS for Younger Children	1 - Appendix 7	23 March 2009
Participant Information Sheet: PIS for Older Children and Young People	1 - Appendix 8	23 March 2009
Participant Consent Form: Professionals	1 - Appendix 12	23 March 2009
Participant Consent Form: Parents	1 - Appendix 13	23 March 2009
Participant Consent Form: Children and Young People	1 - Appendix 14	23 March 2009
GP/Consultant Information Sheets	1 - Appendix 15	23 March 2009
Demographic Information	1 - Appendix 2	23 March 2009
Reply Slip for Children and Young People	1 - Appendix 11	23 March 2009
Reply Slip for Parents	1 - Appendix 10	23 March 2009
Reply Slip for Professionals	1 - Appendix 9	23 March 2009
Evidence of Professional Civil Liability Insurance	1	23 March 2009
Certificate of Employers' Liability Insurance	1	23 March 2009

Membership of the Committee

The members of the Ethics Committee who were present at the meeting are listed on the attached sheet.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Now that you have completed the application process please visit the National Research Ethics Website > After Review

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

We would also like to inform you that we consult regularly with stakeholders to improve our service. If you would like to join our Reference Group please email referencegroup@nres.npsa.nhs.uk.

09/H1006/29	Please quote this number on all correspondence

With the Committee's best wishes for the success of this project

Yours sincerely

Mr Ken Cook
Chair

Email: stephen.tebbutt@northwest.nhs.uk

Enclosures: List of names and professions of members who were present at the meeting

"After ethical review – guidance for researchers"

Copy to: Dr Neil Morris
Senior Lecturer / Chair of School Ethics Committee
The University of Wolverhampton
Wulfruna Street
Wolverhampton
WV1 1LY

North Manchester Research Ethics Committee

Attendance at Committee meeting on 30 April 2009

Committee Members:

Name	*Profession*	*Present*	*Notes*
Dr Osman Abdelatti	Consultant Anaesthetist	No	
Mrs Yvonne Clowes	Clinical Research Manager (Infectious Diseases)	Yes	
Mr Ken Cook	Clinical Services Manager	Yes	
Mrs Heather Evans	Chartered Counselling Psychologist (Lay Member)	No	
Mrs Debbie Hamburger	Social Worker (Lay Member)	Yes	
Miss Annie Herbert	Statistician	Yes	
Mr Richard Hovey		Yes	
Ms Philippa Jones	Pharmacist	Yes	
Rev Dr Clare McBeath	Baptist Minister / Chaplain	Yes	
Mr Rama Mohan	Consultant Orthopaedic Surgeon	No	
Mrs Julie Owen		Yes	
Dr Narveshwar Sinha	Staff Grade Ear Nose & Throat Surgeon	No	
Ms Julie Wray	Lecturer (Nursing) / Research Fellow	No	

Also in attendance:

Name	*Position (or reason for attending)*
Mr Stephen Tebbutt	Co-ordinator

[redacted] NHS
NHS Foundation Trust

Research & Development
[redacted]

Miss Lucy Wheen
Primary Care Mental Health Service
[redacted]

Ref: SC/LSRA

Direct Line: [redacted]

29th June 2008

Dear Lucy,

Re: NHS Trust Approval to Proceed

Project REC Reference: 09/H1006/29
SPEAR Reference: 0844
Project Title: A grounded theory approach to understanding the current diagnosis and treatment of Attention Deficit Hyperactivity Disorder (ADHD) within the National Health Service (NHS).

I am writing to inform you that the above project was approved at the Pennine Care R&D and Audit Panel meeting on the 26th June 2009.

Please take the time to read through this letter carefully and contact the R&D Office should you require any further information. You may need this letter as proof of your approval.

Honorary Research Contracts (HRC)

All researchers with no contractual relationship with any NHS body, who are to interact with NHS patients in a way that directly affects the quality of their care, should hold honorary NHS contracts. For more information on whether you or any of your research team will require an HRC please liaise with the R&D office. **It is your responsibility to inform us if any of your team does not hold NHS contracts.**

Risk and Incident Reporting

Much effort goes into designing and planning high quality research, which reduces risk; however untoward incidents or unexpected events (i.e. not noted in the protocol) may occur in any research project. Where these events take place on trust premises, or involve trust service users, carers or staff, you must report the incident within 48 hours via the Trust incident reporting system. If you are in any doubt whatsoever whether an incident should be reported, please contact the R&D Office for support and guidance.

[redacted] NHS
NHS Foundation Trust

Research Governance, Confidentiality and Information Governance

Whilst conducting this study, you must fully comply with the Research Governance Framework. This can be accessed at http://www.dh.gov.uk website then use the DH search facility. All personnel working on this project are bound by a duty of confidentiality. All material accessed in the trust must by treated in accordance with the Data Protection Act (1998).

Protocol / Substantial Amendments

You must ensure that the approved protocol is followed at all times. Should you need to amend the protocol, please follow the Research Ethics Committee procedures and inform all NHS organisations participating in your research.

Monitoring / Participant Recruitment Details

You will be required to produce a short electronic progress report annually and at completion. Please make sure that you will be able to supply an accurate account of the recruitment targets and numbers recruited for this Trust. Reporting is kept to a minimum; however, if you fail to supply the information requested, the Trust may withdraw approval.

Final Reports

At the end of your research study, we will request a final summary report so that your findings are made available to local NHS staff. The details from this report may be published on the Trust intranet site to ensure findings are disseminated as widely as possible to stakeholders.

On behalf of this Trust, may I wish you every success with your research.

Yours sincerely,

pp

Reagan Blyth
Clinical Effectiveness Manager
Reagan.blyth@penninecare.nhs.uk

Appendix 5

Example of Semi-structured interview questions

Provisional Interview Guide

"Thank you for agreeing to participate in this study. Please remember that you can choose whether or not to answer any questions. You are free to withdraw from the study and stop the interview at any time without giving a reason. This will not affect you in any way. What you say in this interview will only be used for the purposes of the study as stated on your consent form and information sheet."

Professionals

- Please describe your experience of working with children diagnosed with ADHD and their families.
- What is your view of ADHD as a diagnosis?
- How do you feel about current treatment options and practice guidelines around ADHD?
- What aspects of ADHD, if any, do you think require further research and understanding?

Parents

- What is your understanding of ADHD?
- Please describe what led you to seek support for your child's behaviour?
- How do feel about your child's diagnosis of ADHD?
- How, if at all, do you feel your child has been affected by receiving a diagnosis of ADHD?
- How do you feel about the treatment options your child has received?

Children and young people

"Thank you for agreeing to take part in this study. Please remember that you can choose whether or not to answer any questions. If you do not want to answer a question then please tell me. You can stop the interview at any time and nothing bad will happen if you do this. Let's practice what you might say if you don't want to answer something or if you want to stop……

What you say will only be used in this study like it says on your consent form and information sheet. Remember that if you tell me anything that makes me think you or anyone else is in danger of being harmed I will have to tell someone else about that"

- Can you describe to me what you think ADHD is?
- Can you describe to me what it is like to have ADHD?
- How do you feel about being told you have ADHD?
- Can you describe what your treatment for ADHD has been like?
- Can you tell me if there are any things that are helpful or unhelpful for you about ADHD?

I will use prompts and probes to encourage participants to explain and expand upon their responses as required. I will also rephrase questions in a way they feel able to answer if clarification is sought. It is anticipated that questions and techniques for younger children may have to be altered age-appropriately and utilise creative materials to help children explore these concepts.

Prompts and questions

Can you tell me more about….?

Can you describe?

Can you tell me how you felt?

What was that like?

Could you describe what led to ……?

What was going on in your life at that time?

What advice would you give others?

Is there anything else you think I should know or understand better?

Appendix 6

Example of demographic questionnaires

Professionals
Please could you complete the following information about yourself to help us with our research.

Age……..

Gender…….

Professional Qualification…….

Length of time in professional practice…….

Professional Body…….

Current Job Role……...

……..

Length of time in current Job Role……...

Details of any specialist training in ADHD…….....

……..

Children
Please could you complete the following information to help us with our research. You may want to ask someone to help you, like your parents.

Age……..

Gender…….

How old were you when you were first told you had ADHD……..

What medication, if any, do you take……...

Parent/s or carers

Please could you complete the following information about yourself and your child to help us with our research.

Age……..

Gender…….

How old is your child ……

When was your child diagnosed with ADHD…….

What medication, if any, does your child take……

Appendix 7

Example of recruitment letters

School of Applied Sciences
University of Wolverhampton
City Campus - South
Wulfruna Street
Wolverhampton
WV1 1LY

Date:

Dear Sir/Madam,

Title: Understanding Attention Deficit Hyperactivity Disorder (ADHD): A research project

I am a Counselling Psychologist in Training and am currently undertaking research under the supervision of the University of Wolverhampton for Child and Adolescent Mental Health Services in [redacted] This letter is inviting you to take part in the above research study. Please find the enclosed information sheet which provides an outline of the study and what is involved. It is important that you read this information carefully before you decide whether or not to take part in this research. Please feel free to discuss this with other people before making a decision.

Please contact me on the contact information provided if you would like any further information.

Thank you for your time.

Yours Sincerely,

Lucy Fearns
Counselling Psychologist in Training/Researcher.

Tel: [redacted]
Email: [redacted]

Supervised by Dr John Bergin
Tel: [redacted]
Email [redacted]

School of Applied Sciences
University of Wolverhampton
City Campus - South
Wulfruna Street
Wolverhampton
WV1 1LY

Date:

Dear parent/carer,

Title: Understanding Attention Deficit Hyperactivity Disorder (ADHD): A research project

I am a Counselling Psychologist in Training and am currently undertaking research under the supervision of the University of Wolverhampton for Child and Adolescent Mental Health Services in [redacted]. This letter is inviting you and your child to take part in the above research study. Please find the enclosed information pack which provides an outline of the study and what is involved. It is important that you read this information carefully before you decide whether or not to take part in this research. Please feel free to discuss this with other people before making a decision.

I would also like to ask that you consider whether you would like to allow your child to participate in this research. I have enclosed information sheets for children and ask that you read this through with them to allow you to make a decision.

Please do not hesitate to contact me on the contact information provided if you would like any further information.

Thank you for your time.

Yours sincerely,

Lucy Fearns
Counselling Psychologist in Training/Researcher.

Tel: [redacted]
Email: [redacted]

Supervised by Dr John Bergin
Tel: [redacted]
Email: [redacted]

Appendix 8

Example of information sheets

Information sheet for parent(s) or carer(s).
Title: Understanding Attention Deficit Hyperactivity Disorder (ADHD): A research project

You and your child are being invited to take part in the above research study. Before you decide whether or not to take part, it is important that you understand why the research is being carried out and what it involves. Please take the time to read the following information carefully and discuss it with others if you wish.

I would also like to request that you take the time to read the children's information sheet and discuss this with your child to help them make a decision about whether or not to take part. There are two copies of this sheet for younger and older children, please choose which you think is most appropriate for your child's level of understanding. If you and your child agree for them to take part please help them to complete the return slip and return this in the envelope provided.

Please contact Lucy Fearns ([redacted]) if there is anything that is unclear or if you would like further information. Thank you for reading this.

About the study
This study will be looking at how Attention Deficit Hyperactivity Disorder (ADHD) is diagnosed and treated. We are trying to understand the experiences of health professionals, parents/carers and children who are currently in contact with the Child and Adolescent Mental Health Services in [redacted].

What is the purpose of this study?
The purpose of this study is to gain an understanding of ADHD. It is expected that this will add to our understanding of what it is like to live with ADHD.

Why have I been chosen?
You and your child have been asked to take part as your child currently attends appointments at Child and Adolescent Mental Health Services in [redacted].

Do I have to take part?
It is entirely up to you to decide whether or not you or your child takes part. If you decide to take part you will be given this information sheet to keep and asked to sign a consent form. You have the right to withdraw, without giving a reason, anytime before, during or up to two weeks after the interview has taken place. If you decide to withdraw after two weeks of the interview taking place your information will still be used in the study. Nothing you say or do during the research will affect the standard of care your child will receive. If your child decides to take part we ask that you also sign their consent form to agree to this.

What will happen if I take part?
If you do decide to take part you be asked to complete a consent form and some information about yourself. You will then be asked to take part in an interview with the researcher. During this interview your experiences, thoughts and feelings about ADHD will be listened to with respect. The interview will last approximately one hour but if you have more or less to say then this will be respected. If you agree to

take part we will contact you and invite you to attend an interview appointment at the Child and Adolescent Mental Health Service at a convenient time for you. The interview will be tape-recorded. It is also important to understand that your participation in the interview is for research purposes only and will not in any way be a therapeutic visit for you or your child.

If you and your child agree for your child to take part they will also be invited to attend an interview. This will also be recorded. You will not be able to take part in your child's interview. Your child's interview will not in any way be a therapeutic visit.

What are the possible disadvantages or risks of taking part?
There are no identified disadvantages to taking part in this study. The possible risks of taking part in this study are that talking about some of your experiences of ADHD may cause you some upset or distress. You will not have to answer any question which you feel will cause you upset. If this happens, you will be able to contact the researcher using a contact number provided to allow you to discuss any queries or questions you may have.

What are the possible benefits of taking part?
There is no intended direct benefit to you or your child. However, it is hoped that this study will improve researchers and health professionals understanding of ADHD and impact on future management of children's behaviour problems.

Will my information be kept confidential?
All information, which is collected about you during the course of the research, will be kept confidential and you will not be identified. The only circumstance in which confidentiality will be broken would be if you were to tell me that you may harm yourself or another person. The tape recordings will be kept in a locked cabinet and will only be identified through a number known to the researcher. The tapes will be typed out, then destroyed and five years after the research is complete any papers will be shredded. Please note that if your child decides that they would like to take part and you agree then their information will also be kept confidential and you will not be told what they have said. Any information where you or your child may be identified will be made anonymous by using pseudonyms to replace the information. Direct quotations of interviews will be used however any identifiable information will be made anonymous. As a member of the British Psychological Society I am bound to working in accordance with the Society's guidelines and code of ethics. You can request a copy of these guidelines.

What will happen to the results of the study?
After the research study has ended it is our aim to publish the results of this study. You will not be identified in any way in any published research. A summary report of the findings will be written for those taking part in the study. You can indicate on the consent form if you would like to request a copy of this summary.

Who is organising the research?
This study is being organised and funded by the University of Wolverhampton.

Who has reviewed the study?
The study has been reviewed by NHS and University Ethics Committees who have agreed to this study being carried out within the Child and Adolescent Mental Health Services in [redacted].

Who can I contact for further information?
If you have any queries please contact Lucy Fearns on [redacted]). This study is being supervised by Dr John Bergin and his contact details are ([redacted]

What should I do if I decide to participate?
If you agree to take part in this study, you will need to sign the return slip and return this in the envelope provided **within one week** of receiving this letter. You will then be contacted to arrange an interview. At this appointment you will be reminded of your rights within the study and asked to sign a consent form.

If you and your child agree for your child to take part in this study, you will also need to sign the return slip for your child and return this in the envelope provided **within one week** of receiving this letter. You or your child will then be contacted to arrange an interview. At this appointment you and your child will be reminded of your child rights within the study and you will both be asked to sign a consent form for your child.

If you decide not to take part, thank you for reading this information and we wish you well.

Information sheet for younger children
Title: Understanding Attention Deficit Hyperactivity Disorder (ADHD): A research project

You are being invited to take part in a research study. A research study is a way of finding out about something. Before you decide whether or not to take part, we would like you to understand what we are trying to find out and what it would involve for you.

Please read this leaflet carefully and talk about it with someone else, you will need to talk to a parent or carer about it. A carer is the person who is responsible for you and looks after you.

If there is anything that you don't understand or if you would like more information you can ask Lucy, her telephone number is [redacted].

Thank you for reading this.

What is it about?
It is about ADHD and how you think and feel about it. We will also ask children's parents or carers and the people that work at the Child and Adolescent Mental Health Services about what they think and feel about ADHD.

What is the purpose of this study?
The purpose of this research is to understand what is like to be told you have ADHD and what is helpful and unhelpful for you. We hope that this will help people who work with children and young people to learn something new about ADHD.

Why have I been asked?
You have been asked to take part as you go to appointments at the Child and Adolescent Mental Health Services in [redacted] Trust and you have been told that you have ADHD.

Do I have to take part?
No. You do not have to take part in this study and only you can decide if you would like to. You can choose to talk to other people about it if you want to.

You will be able to change your mind at anytime up to two weeks after you have taken part. If you decide not to take part or to stop this will be ok and nothing bad will happen because of it.

If you decide to take part you will be given this information sheet to keep and you will be asked to sign your name on a form to agree. A parent or carer will also be asked to sign the form too, if you are not sure who this should be please ask Lucy.

What will I have to do?
You will be asked to take part in an interview with Lucy. An interview is a talk between you and Lucy. You will be asked some questions, and Lucy will listen to what you say. The talk will last about 1 hour but if you only have a few things to say

it could be shorter or if you have a lot to say it could be longer. We would like to tape record what you say to Lucy.

Will anything bad happen?
Sometimes talking about difficult things like ADHD can be upsetting. But if you find a question upsetting you won't have to answer and you can stop at any time. You can also contact Lucy or speak to your worker at the Child and Adolescent Mental Health Services about it.

What will I get from taking part?
You might not get any benefits from taking part in the study. But by telling people how you think and feel about ADHD we hope it will help other people understand it better.

Will anyone know what I say?
No one will know your name or what you have said. You can choose whether you tell anyone else. The only thing that we do have to tell other people about is if you say someone has broken the law or that you or someone else is in danger or at risk.

Involvement of General Practitioner/ Family Doctor (GP).
If you decided to take part we will need to tell your GP/doctor that you have agreed to this. In this case, we will send a letter to your GP telling them you have agreed to take part and we will send them a copy of this information to keep. They will not know what you have said in your interview.

What will happen to the results of the study?
After the study has ended the information might be printed in a book or magazine but no one will know your name or what you said. You will be able to see what the study finds out if you would like, you can ask Lucy for a copy of this.

Who can I contact for further information?
If you have any questions please contact Lucy on ([redacted]). This study is supervised by Dr John Bergin his contact details are ([redacted]).

What should I do if I want to take part?
If you decide you would like to take part you will need to make sure that a parent or carer also agrees for you take part.

You and a parent or carer will need to sign your names on the reply slip and post it in the envelope provided **within one week.**

We will then contact you or your parent or carer to arrange an interview. You will be reminded that you can stop the interview at any time and change your mind.

If you decide you do not want to take part, thank you for reading this information and we wish you well.

Information sheet for older children and young people.
Title: Understanding Attention Deficit Hyperactivity Disorder (ADHD): A research project

You are being invited to take part a research study. Before you decide whether or not to take part, we think it is important that you understand why the research is being carried out and what it would involve for you. Please read this information carefully and discuss it with others if you wish, you will need to discuss it with a parent or carer. A carer is the person who is responsible for you and cares for you.

Please contact Lucy if there is anything that is unclear or if you would like further information. Her telephone number is [redacted].Thank you for reading this.

About the study
This study is about ADHD and how you think and feel about it. We will also ask children's parents or carers and the people that work at the Child and Adolescent Mental Health Services about what they think and feel about ADHD.

What is the purpose of this study?
The purpose of this research is to understand what is like to be told you have ADHD and what is helpful and unhelpful for you. We hope that this will help people who work with children and young people to learn something new about ADHD.

Why have I been chosen?
You have been asked to take part as you attend appointments at the Child and Adolescent Mental Health Services in [redacted].

Do I have to take part?
No. You do not have to take part in this study and only you can decide if you would like to. If you decide to take part you will be given this information sheet to keep and you will be asked to sign a form to agree to take part. A parent or carer will also be asked to sign the form too. If you are not sure who this should be please ask Lucy.

You will be able to change your mind at anytime before, during or up to two weeks after you have taken part. If you decide not to take part or to stop this will be ok and nothing bad will happen because of it.

What will happen if I take part?
You will then be asked to take part in an interview with Lucy. During this interview you will be asked some questions, and your thoughts and feelings about ADHD will be listened to with respect. The interview will last about one hour but if you only have a few things to say it could be shorter or if you have a lot to say it could be longer. If you agree to take part Lucy will contact you or a parent or carer and invite you to attend an interview. We would like to tape record the interview.

What are the possible disadvantages of taking part?
It is possible that things might come up that may be up setting for you. But if you find a question upsetting you won't have to answer and you can stop the interview at any time. You can also contact Lucy on the number provided or speak to your worker at the Child and Adolescent Mental Health Services about it.

What will I get from taking part?
You might not get any benefits from taking part in the study. But by telling people how you think and feel about ADHD we hope it will help other people understand it better.

Will anyone know what I say?
All your information will be kept confidential, this means that no one will know what you have said and no one else except the research team will know your name. You can choose whether you tell anyone else. The only thing that we do have to tell other people about is if you say someone has broken the law, or that you or someone else is in danger or at risk.

What will happen to the results of the study?
After the research study has ended the information might be published but no one will know your name or what you said. You will be able to have a summary of the findings of the research if you would like one. Just ask Lucy to send you a copy.

Contact for further information
If you have any questions please contact Lucy on (This study is supervised by Dr John Bergin and his contact details are ( ).

What should I do if I decide to take part?
If you agree to take part in this study, you will need to sign your name on the return slip and ask your parent or carer to sign it too. Then it can be returned in the envelope provided **within one week**. You or your parent or carer will then be contacted to arrange an interview. You will be reminded that you can stop the interview at any time and change your mind.

If you decide you do not want to take part, thank you for reading this information and we wish you well.

Information sheet for professionals

Title: Understanding Attention Deficit Hyperactivity Disorder (ADHD): A research project.

You are being invited to take part in the above research study. Before you decide whether or not to take part, it is important that you understand why the research is being carried out and what it involves. Please take the time to read the following information carefully and discuss it with others if you wish. Please contact the researcher if there is anything that is unclear or if you would like further information. Thank you for reading this.

About the study
This study will be looking at the current diagnosis and treatment of ADHD. We are trying to understand the experiences of health professionals, parents and children who are currently in contact with the Child and Adolescent Mental Health Services in [redacted].

What is the purpose of this study?
The purpose of this study is to gain an understanding of ADHD from people within the National Health Service. It is expected that this will contribute to current knowledge and theories in the area of ADHD.

Why have I been chosen?
You have been asked to take part as you currently work within the Child and Adolescent Mental Health Services in Pennine Care NHS Foundation Trust and are registered with a professional body, i.e. BACP, BPS. You should also have some experience of working with children and young people who have been diagnosed with ADHD. We are inviting other professionals from these services and also parents and children to take part.

Do I have to take part?
It is entirely up to you to decide if you want to take part. If you decide to take part you will be given this information sheet to keep and asked to sign a consent form. You will also have the right to withdraw from the research, without giving a reason, anytime before, during or up to two weeks after the interview has taken place. If you do withdraw before this point any information already collected will be destroyed. If you decide to withdraw after two weeks of the interview taking place your information will still be used in the study.

What will happen if I take part?
If you do take part you will be asked to sign consent form and complete some information about yourself. You will then be asked to take part in an interview with the researcher. During this interview your experiences, thoughts and feelings about ADHD will be listened to with respect. The interview will last approximately one hour but if you have more or less to say then this will be respected. If you agree to take part we will contact you and invite you to attend an interview at a convenient time for you. The interview will be tape-recorded. You will be able to refuse to answer any questions and withdraw at any time up to two weeks following the interview.

What are the possible disadvantages of taking part?
There are no identified disadvantages to taking part in this study. However, if this happens, you will be able to contact the researcher using a contact number provided to discuss any queries or questions you may have.

What are the possible benefits of taking part?
There is no intended direct benefit to you. However, it is hoped that this study will improve researchers and health professionals understanding of ADHD and impact on future management of children's behaviour problems.

Will my information be kept confidential?
All information, which is collected about you during the course of the research will be kept confidential and you will not be identified. The only circumstance in which confidentiality will be broken would be if you were to tell that you may harm yourself or another person. The tape recordings will be kept in a locked cabinet and will only be identified through a number known to the researcher. Following transcription the tapes will be destroyed and five years after the research is complete any papers will be shredded. Any identifiable information will be made anonymous using pseudonyms. Direct quotations from your interview will be used however all identifiable information will be made anonymous. As a member of the British Psychological Society the researcher is bound to working in accordance with the Society's guidelines and code of ethics. You can request a copy of these guidelines.

What will happen to the results of the study?
After the research study has ended it is our aim to publish the results of this study. You will not be identified in any way in any published research. A summary report of the findings will be written for those taking part in the study. You can indicate on the consent form if you would like to request a copy of this summary.

Who is organising the research?
This study is being organised and funded by the University of Wolverhampton.

Who has reviewed the study?
The study has been reviewed by the Local NHS Research Ethics Committee, Pennine Care NHS Foundation Trust and The University of Wolverhampton, School of Applied Sciences Research Ethics Committee, who have agreed to this study being carried out within the Child and Adolescent Mental Health Services in [redacted] Trust.

Who can I contact for further information?
If you have any queries please contact Lucy Fearns on ([redacted] This study is being supervised by Dr John Bergin and his contact details are ([redacted]).

What should I do if I decide to participate?
If you agree to take part in this study, you will need to sign the return slip and return this in the envelope provided **within one week** of receiving this letter. You will then be contacted to arrange an interview. At this appointment you will be reminded of your rights within the study and asked to sign a consent form. **If you decide not to take part, thank you for reading this information and we wish you well.**

Appendix 9

Example of reply slips

Reply slip for parent/s or carers

Title:
Understanding Attention Deficit Hyperactivity Disorder (ADHD):
A research project

Name of Researcher: Lucy Fearns ([redacted])
Name of supervisor: Dr John Bergin ([redacted])

I would like to take part in the research named above. I understand that my information will be kept confidential and I am free to withdraw at anytime before, during and up to two weeks after I have taken part. I also understand that if I decide to withdraw, this will not affect me or the care my child receives in any way.

I agree to the researcher contacting me on the number below to arrange an interview date convenient to me.

Signed_____ Date:_____

Name_____
_

Address
_____

Telephone Number
_____

Please note this is not a consent form. You will be asked to sign a consent form for you and/or your child before taking part in the interview.

Reply slip for children and young people

Title:
Understanding Attention Deficit Hyperactivity Disorder (ADHD):
A research project

Name of Researcher: Lucy Fearns ([redacted])
Name of supervisor: Dr John Bergin ([redacted])

I would like to take part in this research study. I understand that my details will be kept confidential and I am able to withdraw (change my mind and stop) at anytime before, during or up to two weeks after I have taken part. I also understand that if I decide to withdraw, this will not affect me in any way.

I agree to Lucy contacting me or one of my parents on the number below to arrange a time for me to attend an interview.

Signed_____ (child or young person) Date:_____

Name_____ (child or young person)

Signed_____(parent/carer) Date:_____

Name_____(parent/carer)

Address
_____

Telephone Number
_____

Please tick who you would like us to contact to arrange the interview.

- ❑ Please contact me
- ❑ Please contact my parent/carer.
- ❑ You can contact me or my parent/carer.

Reply slip for professionals

Title:
Understanding Attention Deficit Hyperactivity Disorder (ADHD):
A research project

Name of Researcher: Lucy Fearns ([redacted])
Name of supervisor: Dr John Bergin ([redacted])

I would like to take part in the research named above. I understand that my involvement will be kept confidential and I am free to withdraw at anytime before, during or up to two weeks after have I have taken part. I also understand that if I decide to withdraw, this will not affect me in any way.

I agree to the researcher contacting me on the number below to arrange an interview date convenient to me.

Signed_____ Date:_____

Name_____
_

Address
_____

Telephone Number
_____

Please note this is not a consent form. You will be asked to sign a consent form before taking part in the interview.

Appendix 10

Example of Consent Forms

Research consent form for parent/s or carers

Title: Understanding Attention Deficit Hyperactivity Disorder (ADHD): A research project

Name of Researcher: Lucy Fearns ([redacted]
Name of supervisor: Dr John Bergin ([redacted]

Please read the following information carefully and ask if there is anything you do not understand or would like more information about before you choose to sign.

Please initial box

1. I confirm that I have read and understood the information sheet for the above study and had the opportunity to ask questions. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at anytime up to two weeks after my interview, without giving any reason and that this will not affect me or the care my child receives in any way. ☐
3. I understand that my information will still be used if I attempt to withdraw after two weeks of taking part in my interview. ☐
4. I understand that I will not be identifiable in any way in written or published reports of the research investigation. ☐
5. I agree to take part in the above study. ☐
6. I agree for my interview to be recorded and I understand that any direct quotations used will be made anonymous. ☐
7. I understand that a summary of the research findings will be available when the study has ended. (please tick the box below if you would like to request a copy). ☐

_____	_____	_____
Name	Date	Signature
_____	_____	_____
Name of researcher	Date	Signature

❑ I would like to receive a copy of the summary of the research findings.
If you tick this box a copy of the findings will be sent to your address when the study is finished.

Research consent form for professionals

Title: Understanding Attention Deficit Hyperactivity Disorder (ADHD): A research project

Name of Researcher: Lucy Fearns ([redacted]
Name of supervisor: Dr John Bergin ([redacted])

Please read the following information carefully and ask if there is anything you do not understand or would like more information about before you choose to sign.

Please initial box

1. I confirm that I have read and understood the information sheet for the above study and had the opportunity to ask questions. ☐
2. I understand that my participation is voluntary and that I am free to withdraw anytime up to two weeks after my interview, without giving any reason and that this will not affect me in any way. ☐
3. I understand that my information will still be used if I attempt to withdraw after two weeks of taking part in my interview. ☐
4. I understand that I will not be identifiable in any way in written or published reports of the research investigation. ☐
5. I agree to take part in the above study. ☐
6. I agree for my interview to be recorded and I understand that any direct quotations used will be made anonymous. ☐
7. I understand that a summary of the research findings will be available when the study has ended. (please tick the box below if you would like to request a copy). ☐

_____	_____	_____
Name	Date	Signature
_____	_____	_____
Name of researcher	Date	Signature

❑ I would like to receive a copy of the summary of the research findings.
If you tick this box a copy of the findings will be sent to your address when the study is finished.

Research consent form for children and young people
Title: Understanding Attention Deficit Hyperactivity Disorder (ADHD): A research project
Name of Researcher: Lucy Fearns ([redacted]
Name of supervisor: Dr John Bergin ([redacted]

Please read the information below carefully before you choose to sign your name. If there is anything you do not understand or would like more information about please ask.

Please initial box

1. I have read the information sheet about this study and I understand it. I have been able to ask questions about it. ☐
2. I understand that it is my choice to take part and I can change my mind at anytime up to two weeks after the interview. I do not have to give a reason to change my mind and nothing bad will happen if I do. ☐
3. I understand that if I change my mind (withdraw) two weeks after I have taken part in the interview my information will still be used. ☐
4. I understand that no one will know my name or what I have said in the study. ☐
5. I agree to take part in the study. ☐
6. I agree for my GP to be told about my involvement in this study. ☐
3. I agree for my interview to be recorded and I understand that my name will be changed (made anonymous) if anything I have said is used in the study (quoted). ☐
7. I understand that I can have a summary of the findings when they study has finished. (please tick the box below if you would like to have a copy).

Name	Date	Signature
Name of researcher	Date	Signature

- ☐ Please this box if you would like a copy of the findings to be sent to your address when the study is finished.

Parents/carers please counter-sign your child's consent form only if you agree to them taking part. A carer must be someone with parental responsibility. If you are not sure who this is please ask Lucy Fearns ([redacted]
I consent to my child taking part in the above research and can confirm that the above information has been provided.

Name	Date	Signature